



Preventative Women's  
Health Care for Women  
with Disabilities

*Guidelines for  
General Practitioners*

*Background and  
Literature Review*

*“The basic health care needs of women with disabilities are identical to the general female population, yet they do not receive the same level of preventative health care”*

**Preventative Women’s Health Care for Women with Disabilities - Guidelines for General Practitioners. Background and Literature Review**

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## BACKGROUND

One of the NSW Cervical Screening Program aims is to improve the quality of, and access to, cervical screening services provided by general practitioners to women with disabilities in NSW. Through an assessment of the literature and widespread consumer consultation, the NSW Cervical Screening Program identified that clinical guidelines for service providers who were caring for women with disabilities were not readily available. The NSW Cervical Screening Program formed a partnership with the Centre for Developmental Disability Studies, University of Sydney, to develop the guidelines and to design a small-group learning activity for general practitioners to promote them.

A consultative committee was set up consisting of representatives from the Royal Australian College of General Practitioners; Divisions of General Practice; NSW Cervical Screening Program; FPA Health; consumer representative from the Council for Intellectual Disability and People with Disabilities (see Appendix). The Centre for Developmental Disability Studies conducted a detailed literature review which identified three main causes for reduced screening rates amongst women with disabilities: knowledge and attitudes of general practitioners; knowledge of women with disabilities about their preventive health needs; and accessibility to general practitioners' premises and examination equipment. A draft set of guidelines was prepared for consideration by the consultative committee. They were based on the evidence of the literature review and provided information to general practitioners about issues facing women with disabilities. The draft guidelines were then circulated to a range of advocacy groups around NSW, inviting comments for inclusion into the final document. Responses from the advocacy groups were collated and considered by the consultative committee and the guidelines amended where appropriate. The guidelines were focus-tested with women with disabilities, general practitioners and the NSW Cervical Screening Program's women and general practitioner task forces. The focus-group meetings were held at venues that accommodated all ranges of disabilities and needs (e.g., transport and carers' costs).

The final Guidelines were published by NSW CSP. The guidelines address the following areas: barriers to effective screening, consent, communication strategies, access and alternative examination

techniques, and women's health management in specific areas (cervical screening, menstrual management, breast screening, menarche, sexual assault, sexual health, contraception, pregnancy choices and menopause).

Two pilot sites were identified to run the small-group learning activity. General practitioners at those sites were consulted to identify and reflect on their own personal learning needs in relation to women with disabilities and their preferred style of presentation. General practitioners were also requested to identify specific topics for inclusion into the small-group learning activity. The selection included topics such as communication techniques, truths and myths about women with disabilities, sexuality and disability, barriers to screening, practical hints and screening techniques, information about enhanced primary care health assessment funding, legal responsibilities and the Guardianship Tribunal and women's preventive health and disabilities. This consultation ensured that the small-group learning activity could be tailored to meet general practitioners' needs.

In order to make the learning activity attractive to general practitioners, an application was made to the Royal Australian College of General Practitioners' Quality Assurance & Continuing Professional Development Program (QA & CPD) to endorse the small-group learning activity and to allocate 8 CPD points. The small-group learning activity was piloted in two regional divisions of general practice where a variety of learning techniques and topics were presented. The learning activity utilised peer support, interaction and reflection and was designed to enhance general practitioners' performance, competence, attitudes, skills and knowledge, in the field of women with disabilities, as it relates to clinical and professional practice. The small-group learning activity is now being offered widely to division of general practice across NSW. The guidelines will be circulated to all general practitioners across NSW and will be placed on the NSW Cervical Screening website for wide access.

In summary, the project aimed to develop evidence-based guidelines and implement them through a small-group learning activity for general practitioners. Preliminary evaluation has indicated that the small-group learning activity has been successful in implementing the guidelines by improving general practitioners' knowledge, understanding and delivery of quality Pap test services to women with disabilities.

## LITERATURE REVIEW

With increasing life expectancy and advances in health care, the proportion of women with disabilities in the population is growing (Nosek & Howland, 1997). This review examines the uptake of preventative women's health care practices in women with disabilities, with particular reference to breast and cervical screening rates. The review will also identify the barriers to screening services that are perceived by women and general practitioners. Strategies for improving screening practices for women with disabilities will be discussed.

### 1. DISABILITY PREVALENCE AND DEFINITIONS

*According to the Australian Bureau of Statistics (1999), a person is classified as having a disability if they report one or more of 17 specified limitations, restrictions or impairments lasting at least 6 months. These cover a range of physical, psychiatric, neurological, intellectual and sensory conditions. Inclusive of this definition is the notion that disability may be congenital or acquired. In the Australian Bureau of Statistics (ABS) survey, Disability, Ageing and Carers, it was noted that in 1998, 19.3% of the Australian population reported having a disability (ABS 1999).*

"Intellectual disability", the term used in Australia and Europe, is known as "mental retardation" in the USA and "learning disability" in the UK. "Developmental disability" is a severe chronic disability, due to a mental or physical impairment, or a combination of both, which is likely to continue indefinitely and is manifested in the "developmental period" of life. In NSW, this is usually accepted to be before the age of 18 years. The term therefore includes conditions such as cerebral palsy and autism, where the person may or may not have an intellectual disability.

#### 1.1 Health care in women with disabilities

Women with disabilities are acknowledged to be one of the most disadvantaged groups in today's society (Thierry, 2000). Although many consumers complain about the quality of their health care, people with disabilities have been identified to be one of the most under provided for minority groups in the health care system (Iezzoni et al, 2001; Veltman et al, 2001). They often lack opportunities to engage in preventative health care activities and do not have adequate access to primary health care, hospital care and long term care services (Veltman et al, 2001). Many factors that compromise the quality of their care have been identified. These include: short appointment times in which to address their complex

health needs; physical, sensory and communication barriers with health practitioners; and limited financial resources (Iezzoni et al, 2001). In addition, people with disabilities report difficulties in identifying health professionals who have adequate training in disability related issues (Oshima et al, 1998).

Physicians frequently underestimate the quality of life for people with disabilities, and this may result in biased health advice being given (Oshima et al, 1998). Women with disabilities have historically faced double discrimination because of their disability and gender (Becker et al, 1997). It has been observed that,

*"Women with disabilities in particular, report bias and prejudice in accessing reproductive health care services" (Oshima et al, 1998, p.1270).*

## 2. WOMEN'S HEALTH ISSUES

The clinical management of women's health issues for women with disabilities should be approached in the same way as for women in the general population (Palmer, 1999). Successful management requires: awareness of and investigation into a range of typical women's health issues; identification of appropriate support resources for the woman; and obtaining the woman's informed consent (Messinger-Rapport et al, 1997; Palmer, 1999). Clinical management of women's health issues for women with disabilities should be guided by the following principles:

- ◆ women with disabilities have the right to current standards of care and a full range of management options;
- ◆ the woman's best interests are the highest priority, rather than the interests of others;
- ◆ education is the first stage in the continuum of least restrictive management alternatives;
- ◆ an obligation exists to overcome any physical, cognitive and communication difficulties that may be present (Palmer, 1999).

The main women's health issues identified as being important by women with disabilities include:

- ◆ the woman and her carer's knowledge and attitudes towards sexuality and disability;
- ◆ menstruation and hygiene management;
- ◆ contraception and pregnancy management;
- ◆ menopause and hormone replacement therapy;

- ◆ current or previous history of sexual abuse;
- ◆ preventative health care measures, such as cervical and breast screening (Palmer, 1999; Nosek, 1996).

The recommended clinical management for these health problems follows the same principles as for other women in the population (Palmer, 1999). These include:

- ◆ hormone replacement therapy, where indicated, for women with late menarche;
- ◆ standard hygiene management for menstruation;
- ◆ reassurance during physical examinations rather than the use of sedation;
- ◆ prescription of the most suitable, not the most convenient, contraceptive;
- ◆ provision of dietary and fitness education as well as hormone replacement (where indicated) for women experiencing menopause (Palmer, 1999).

### 3. RECOMMENDED PREVENTATIVE HEALTH CARE SCREENING

#### 3.1 Cervical Screening

Cervical cancer is a common cancer worldwide and is a major cause of morbidity and mortality amongst women (Parkin, 1999). Risk factors for precancerous and cancerous lesions of the cervix are age, sexual behaviour, smoking, socioeconomic status and ethnicity (NHMRC, 1996). The Papanicolaou smear (Pap smear) is the primary screening tool for detecting cervical carcinoma and its precursors (NHMRC, 1996). The reliability of this technique is dependent on the expertise of the professional taking the smear and the person examining it (Peters, 1998). Improvements in cervical cancer survival rates have been linked to detection of precancerous lesions by Pap smear and their early treatment (Gatta et al, 1999). In Australia it is currently recommended that:

*"All women who have been sexually active at any stage in their lives to have a Pap smear every 2 years until age 70 years. Pap smears may cease at the age of 70 years for women who have had two normal Pap smears within the last five years. Women over 70 years who have never had a Pap smear, or who request a Pap smear should be screened" (Australian Institute of Health and Welfare, 1999).*

A cervical screening register exists in each Australian State and Territory. The aim of cervical screening registers is to reduce morbidity and mortality from cervical cancer by ensuring quality control in smear collection and emphasising the importance of routine screening (NHMRC, 1996).

### 3.2 Breast Screening

Breast cancer affects one in fourteen women in Australia with the incidence slowly increasing (NHMRC, 1996). Breast cancer is reported to be the most common form of cancer associated with death in Australian women (Australian Institute of Health and Welfare, 2002; Cowie & Fletcher, 1998; Glasziou & Irwig, 1997). Screening for breast cancer typically includes three techniques: breast self-examination; breast examination by a doctor; and mammography (NHMRC, 1996).

*Breast self examination (BSE)* was traditionally thought to be a logical method of cancer detection as most breast cancers are found by women themselves (NHMRC, 1996). A meta-analysis of BSE effectiveness research found BSE to be beneficial in terms of detecting the size of the breast tumour and the absence of nodal involvement at the time of diagnosis (Hill et al, 1988; NHMRC, 1996). BSE is therefore a useful component of preventative health screening procedures, however it is not recommended as the primary detection tool (NHMRC, 1996).

*Regular examination* by a doctor is the traditional method of screening and is advised to be performed at the same time as the Pap test (NHMRC, 1996). There is no published evidence as to whether this method of screening is effective in reducing the morbidity and mortality from breast cancer and is therefore not recommended as the primary diagnostic screening tool, but is rather a secondary evaluation tool (NHMRC, 1996).

*Mammography* has been thought to be an effective screening tool for reducing the mortality from breast cancer (NHMRC, 1996). Several well respected clinical trials have demonstrated that mammographic screening can reduce the mortality of breast cancer by 20-30% (Ferrini et al, 1996; NHMRC, 1996). Although this evidence has recently been challenged (Bonfill et al, 2002; Olsen & Gotzche, 2002), the current recommendation for women over the age of 50 years to have routine mammographic breast screening every two years still applies (Ferrini et al, 1996; Glasziou & Irwig, 1997). There is debate about the benefits and frequency of optimal screening for women aged 40-49 years (Ferrini et al, 1996; Glasziou & Irwig, 1997).

#### 4. PREVENTATIVE SCREENING RATES IN WOMEN WITH DISABILITIES

Population studies of women with disabilities in general, and across various diagnostic groups in particular, have demonstrated that women with disabilities do not receive the same level of preventative health care as their peers (Branigan et al, 2001; Cheng et al, 2001; Davies & Duff, 2001; Iezzoni et al, 2001; Nosek & Howland, 1997; Pearson et al, 1998; Stein & Allen, 1999; Theiry, 2000; Turk et al, 1997). The reported cervical and breast screening rates amongst women with disabilities fall well below the recommended guidelines.

The National Centre for Health Statistics (NCHS) conducted a US population survey into the use of screening and preventative services amongst women with disabilities. The NCHS examined the responses from 77,762 women aged 18 and older, including women with physical, sensory and mental health impairments. In this survey, Iezzoni (2001) found that,

*"...women who were hard of hearing had rates of services closest to the population average, whereas those with major lower extremity mobility problems and serious mental health problems had the largest discrepancies from the average rates... women with major lower extremity difficulties have much lower ( $p < 0.01$ ) odds of receiving a Papanicolaou smears, mammograms, and smoking queries" (Iezzoni et al, 2001).*

Analysis of the Centre for Disease Control and Prevention (CDC) US database between the years 1994-1995 revealed that,

*"...women with functional limitations (FLs) were less likely than women without FLs to have had a Pap test within the previous 3 years, and women aged >65 years with three or more FLs were less likely to have ever had a mammogram compared with similarly aged women with no limitations" (Nosek & Gill, 1998; Theiry, 2000).*

This trend of lower screening rates amongst women with disabilities in general is also seen in for various specific types of disabilities. These data from several studies are summarised in Table 1.

The general female population appears to be well informed about optimal preventative health care and receives regular screening from their general practitioner (Glasziou & Irwig, 1997). In addition, the general population receives education and reminders from the health system to increase their compliance with recommended screening practice (Australian Institute of Health and Welfare, 2000). Yet women with disabilities do not experience this same level of care.

**Table 1:** Preventative screening rates amongst women with specific disabilities

Study	Methods	Participants	Outcomes
Branigan et al, 1999	Survey of cervical screening rates using convenience sample (20% response rate)	Subjects: Women with physical disabilities living in Canada N = 201	54.5% of respondents had received Pap tests every 2-3 years or less frequently, compared to the 68% of women in the 1994 Canadian National Population Health Survey who reported receiving Pap test 3 years or less before the survey.
Cheng et al, 2001	Survey of cervical and breast screening rates	Subjects: Women with multiple sclerosis living in the US N = 713	Overall rates for cervical smear tests, breast examinations and mammography exceeded Health People 2000 recommendations, but rates were highest for the ambulatory group and lowest for the non-ambulatory group ( $p > 0.05$ ).
Davies & Duff, 2001	Survey of breast screening rates	Subjects: English women with learning disabilities, aged 52-90, living in group homes and who regularly accessed a general practitioner N = 58	30% of the sample had never received invitations to attend mammography.
Nosek & Howland, 1997	Case comparison study of pelvic examination rates	Subjects: Women with physical disabilities, eg. spinal injury; polio; cerebral palsy; multiple sclerosis; and connective tissue disorders N = 843, 450 of these with physical disabilities	Women with severe physical disabilities were 6% less likely to receive regular pelvic exams ( $p = .029$ ).
Pearson et al, 1998	Survey of cervical and breast screening rates	Subjects: Women with learning disabilities living in Exeter health district UK N = 62	Of 62 women eligible for cervical screening, 15 (24%) had had a smear test in the previous five years (district average 82%). Of 12 women eligible for breast screening, seven had had breast screening within the last three years (district average 66%).
Stein & Allen, 1999	Retrospective medical record review of cervical screening rates	Subjects: Women with learning disabilities, aged 20-64, living in one English health district N = 398	Only 13% had a recorded Pap test in the previous five years, which is markedly lower than the cervical screening rate for the general female population.
Turk et al, 1997	Telephone questionnaire measuring access to preventative health care	Subjects: Women with cerebral palsy, aged 20-74 years N = 63	92% of the women recalled having had at least one gynaecological examination in their life, while 18% reported having an exam in the past year. Only 22% of the women reported doing breast self-examination, or having someone do one for them, in the past month.

## 5. BELIEFS AND PRACTICES LEADING TO LOWER SCREENING RATES

The general community, including health professionals, hold many myths about the sexuality of people with disabilities (Muir & Ogden, 2001). These myths have been reported to include:

- ◆ disabled women are asexual (Basson, 1998; Becker et al, 1997; Djuretic et al, 1999; Oshima et al, 1998; Peters, 1982; Smeltzer, 2000; Thierry, 2000; Welner, 1998; Welner et al, 1999);
- ◆ only independently functioning women can handle relationships (Basson, 1998);
- ◆ disabled women who are single are celibate (Basson, 1998);
- ◆ disabled women cannot be mothers (Basson, 1998);
- ◆ all disabled women are heterosexual (Basson, 1998);
- ◆ disabled women should be grateful for sexual relationships (Basson, 1998);
- ◆ disabled women are different (Basson, 1998);
- ◆ disabled women do not have sufficient life expectancy to warrant preventative screening (Cheng et al, 2001); and
- ◆ youth and beauty are essential to sexuality (Basson, 1998).

These misconceptions about women with disabilities have influenced the type of preventative health care services that women with disabilities receive. Reproductive health issues have often been ignored in women with disabilities because of the myth that they are asexual beings and therefore not in need of screening services (Becker et al, 1997, Peters, 1982, Welner, 1998). However, women with disabilities have the same risk factors for breast and cervical cancer as women in the general population (Thierry, 2000). Many women with disabilities who do not receive preventative health care services may indeed be sexually active or may have been sexually active at some time.

It is an oversight on the part of a general practitioner to assume that a woman with a disability is unable to be sexually active due to her level of physical impairment (Nosek, 1996). Furthermore, to assume that a woman has never been sexually active on the basis of her disability ignores the fact that women with disabilities are more likely to have experienced sexual abuse than the general female population (Muccigrosso, 1991). Women with disabilities are more likely to experience abuse from attendant carers or health professionals than their peers (Young et al, 1997). They are also more likely to experience a longer duration of abuse (Young et al, 1997). Given the commonly associated communication impairments amongst women with moderate to severe physical or intellectual disabilities, a lack of disclosure to the general practitioner concerning sexual abuse cannot be assumed to mean that it has not occurred.

Therefore, as for women in the general population, women with disabilities are also in need of routine early screening services.

*"Women with disabilities can and do develop premalignant and malignant conditions. These potentially fatal cancers may not be recognised at a treatable stage" (Welner, 1998, p.284).*

Research has demonstrated that a disproportionate number of deaths from breast and cervical cancer occur among women of minority groups, including women with disabilities and low-income groups (Thierry, 2000). This indicates that preventative health care is not always reaching these target groups.

The phenomenon of "diagnostic overshadowing" also affects clinical decision-making. This is where physical or psychiatric conditions are overlooked or misdiagnosed in people with disability, due to symptoms being wrongly attributed to the person's primary disability. Therefore, further investigations may not be pursued and the person may not receive the appropriate treatment. Within a health assessment, if there are no investigations beyond the woman's disability, standard health risks may not be evaluated as they would with another patient (Becker et al, 1997).

## 6. OTHER BARRIERS TO PREVENTATIVE HEALTH SCREENING

The barriers to preventative health screening identified by women with disabilities, general practitioners and researchers can be broadly grouped into three areas: (1) general practitioners' inadequate knowledge and training in the care of women with disabilities; (2) limited knowledge of women with disabilities about their preventative health needs; and (3) difficulties with access to general practitioners' premises and examination equipment.

### 6.1 General Practitioner Knowledge and Training

People with disabilities are vulnerable to adverse health care experiences and one of the factors that compromises their care is general practitioner training (Iezzoni et al, 2001). People with disabilities routinely report difficulties in identifying a general practitioner who has adequate training in disability issues (Oshima et al, 1998). Physicians tend to focus on the person's disability, rather than attending to the needs and questions that brought the person to the physician in the first place (Oshima et al, 1998). The person with the disability can spend a significant portion of the appointment educating the general practitioner about the nature of their disability (Oshima et al, 1998). General practitioners frequently underestimate the quality of life of people with disabilities resulting in biased medical advice and limited treatment options being offered (Oshima et al, 1998).

Inadequate knowledge amongst general practitioners concerning disability issues, coupled with attitudinal barriers, provides one explanation for the low preventative screening rates of women with disabilities (Band, 1998; Iezzoni et al, 2001; Meehan et al, 1995; Singh, 1997; Welner et al, 1999; Wilson & Haire, 1990). A qualitative study by Becker and colleagues examining the experience of women with disabilities in preventative health care, found that a major barrier to effective care was the general practitioner's relationship with the patient. The authors note,

*"Providers were described (by women with disabilities) as uncomfortable treating women with disabilities, insensitive to their needs, and reticent to discuss key reproductive health issues" (Becker et al, 1997).*

In a survey investigating the reasons why women with physical disabilities did not receive Pap smear and breast checks, 29.1% of women stated that they could not find a doctor who suited them (Nosek & Howland, 1997). General practitioners themselves have identified that they lack the necessary skills, knowledge and resources to offer health promotion and screening to women with disabilities (Kerr et al, 1996).

Specifically, the following factors have been identified:

- ◆ inadequate experience in working with women with disabilities;
- ◆ lack of ability to communicate with women with disabilities;
- ◆ lack of confidence;
- ◆ fear amongst staff;
- ◆ the presence of inappropriate stereotypes and negative assumptions about the woman's ability to maintain health;
- ◆ lack of accurate records on previous health;
- ◆ poor exchange of information between health services; and
- ◆ uncertainty about who is responsible for coordinating services (Martin et al 1997).

A study by Oshima and colleagues (1998), examined the preventative health knowledge of internal medicine and gynaecology residents via a case vignette of a woman with tetraplegia. The authors found that less than 17% of the doctors knew how to manage a patient's spasticity, and less than 10% knew how to use positioning strategies to facilitate a successful examination. The authors concluded,

*"This study raises concerns about whether primary care physicians are adequately trained and, indeed, can reasonably be expected to meet the needs of extensively disabled patients. The quality and quantity of information about medical care for disabled patients in medical school curricula must be improved so that physicians, in all fields of practice, will have a better understanding of life with disability, of secondary prevention issues and of disability resources" (Oshima et al, 1998).*

This view was confirmed in a report on the rate of cervical and breast cancer screening amongst women with disabilities by the Centre for Disease Control and Prevention in the US. The author of the report reviewing the data concluded,

*"Most health care professionals have not been adequately trained to address problems and issues related to disability. Providers of screening services must be educated about the special health care needs of women with disabilities..." (Thierry, 2000).*

### 6.2 Knowledge of Women with Disabilities about their Preventative Health Care Needs

Although all women have similar risk factors for cancer regardless of disability, it appears that not all women with disabilities are aware of this fact (Welner et al, 1999). A survey investigating why women with physical disabilities did not receive Pap smear and breast checks found that 5% of the women believed they did not need a pelvic exam because of their disability, and 23.5% of women believed they did not need a mammogram because their risk of getting cancer was very low (Nosek & Howland, 1997). These beliefs are often perpetuated by the health system,

*"Frequently women with disabilities are told (by general practitioners) that pelvic examinations are not necessary because that examination would be too difficult to perform" (Welner et al, 1999, p.459).*

If a woman with a disability perceives that her general practitioner holds erroneous assumptions or negative attitudes about her sexuality she may be dissuaded from asking reproductive health questions (Iezzoni et al, 2001). Indeed, many women with disabilities may not know what questions to ask or may be too embarrassed to ask them (Welner et al, 1999). This lack of dialogue concerning preventative health care is likely to perpetuate general practitioners' attitudes and myths concerning sexuality and health needs of women with disabilities (Peters, 1982).

### 6.3 Accessibility of General Practitioners' Premises and Examination Equipment

The poor accessibility of general practitioner, and other health care provider premises, and of the examination equipment is frequently cited by women with disabilities and researchers as a significant barrier to preventative health care examinations (Becker et al, 1997; Iezzoni et al, 2001; Nosek, 1997; Nosek & Howland, 1997; Peters, 1982; Thierry, 2000; Turk et al, 1997; Veltman et al, 2001; Welner, 1998; Welner et al, 1999). This poor accessibility exists on many levels, including:

- ◆ inaccessible entrances to premises (Veltman et al, 2001);
- ◆ inaccessible bathrooms in premises - a Canadian study of people with physical disabilities found that one third of respondents experienced difficulty accessing their general practitioners' offices and bathrooms (Veltman et al, 2001);
- ◆ inaccessible examination tables - the reason most frequently cited by women with physical disabilities for not taking a pelvic examination is difficulty in getting onto the standard examination table (Nosek, & Howland 1997);
- ◆ inaccessible mobile mammography units i.e. caravans, trailers, etc. (Nosek & Howland, 1997);
- ◆ inaccessible mammography screening equipment, where the woman is unable to assume or maintain the testing position (Nosek & Howland, 1997);
- ◆ compromised physical safety whilst the examination occurs, as the women may be balanced precariously to assume the test position, or be held by nurses or technicians (Nosek & Howland, 1997); and
- ◆ transportation problems (Becker et al, 1997).

Able-bodied members of the community, including general practitioners, can easily underestimate the impact of accessibility for people with disabilities. A U.S. study found that 86-90% of physicians believed that their premises and examination rooms were wheelchair accessible (Oshima et al, 1999). Despite this, many people with disabilities report that they cannot access their general practitioners' rooms or examination equipment. When the same group of physicians were asked how they would assist a patient to transfer onto the examination table: 53-64% stated they would obtain the assistance of a staff member to lift the person onto the table; 40% stated they did not know what they would do; and only 21% reported having access to a height adjustable examination table (Oshima et al, 1999). The authors concluded that,

*"[Physician and gynaecology residents'] knowledge about appropriate transfer and positioning techniques, wheelchair accessibility, spasticity management, and the risks of pregnancy in the context of disability was limited and for some respondents was inaccurate" (Oshima et al, 1999).*

## 7. STRATEGIES FOR INCREASING PREVENTATIVE HEALTH SCREENING

The problem of lower screening rates in women with disabilities has been well documented in the research literature, yet the proposed solutions for increasing screening practices tend to be based on expert opinion only and remain largely untested. The following strategies for increasing preventative screening practice rates amongst women with disabilities have been proposed: (1) general practitioner training in disability awareness, and in effective communication techniques; (2) general practitioner training in the care of women with disabilities, including the use of alternative examination techniques; (3) provision of information to women with disabilities about recommended preventative health care; (4) environmental modifications to general practitioner premises to improve accessibility; and (5) installation of accessible examination equipment and facilities. Each of these proposed strategies is discussed in detail below.

### 7.1 General Practitioner Training in Disability Awareness and Communication

Physicians themselves have identified that they are ill prepared for providing routine gynaecological management to women with disabilities (Kerr et al, 1999), and report a low level of comfort in dealing with these issues (Oshima et al, 1998). It has been hypothesised that,

*"...further education and training regarding the care of women with disabilities would result in improved comfort levels [for physicians]" (Oshima et al, 1998, p.1274)*

Women with disabilities have suggested that general practitioners require disability awareness training to better prepare them to work with women who have disabilities (Becker et al, 1997). The aim of such training is to increase general practitioners' sensitivity to the issues of routine gynaecological management from the perspective of women with disabilities (Becker et al, 1997). It has been suggested that the training should also address the medical and psychological aspects of disability related preventative health care (Beckmann et al, 1989; Nosek & Howland, 1997), as well as myths and attitudes about women with disabilities (Nosek & Howland, 1997).

Another factor contributing to the physicians' discomfort in treating women with disabilities, is their difficulty in communicating effectively with this patient group (Barr et al, 1999). General practitioners identify communication difficulties as the major barrier to providing high quality health care to people with disabilities (Lennox et al, 2001). It has been suggested that communication skills training could increase the doctor's confidence in working with people with disabilities (Muir & Ogden, 2001). It has been recommended that the following issues be specifically addressed in the training:

## Establish Rapport

Rapport should be established with a woman with a disability as with any other patient, prior to commencing a physical examination (Becker et al, 1997; Peters, 1982; Welner et al, 1999). Establishing rapport will facilitate communication of information and help build trust and compliance to proceed to the physical examination (Burbidge, 1999). It is important for the general practitioner to recognise that a woman with a disability may never have received reproductive preventative health care services before, or she may have had negative health care experiences (Becker et al, 1997; Welner et al, 1999). Therefore there may be a level of discomfort, unfamiliarity and a lack of trust (Peters, 1982; Welner et al, 1999). A gentle, non-judgemental and accepting attitude from the general practitioner will assist a woman to overcome these natural psychological barriers (Welner et al, 1999).

Rapport can also be established through the process of obtaining a complete health and psychosocial history, and by encouraging women to ask questions about the physical examination. Many women with disabilities will not know what questions to ask or be too embarrassed to ask. Providing a checklist to complete prior to the examination may help the woman to prepare psychologically for the examination, and will facilitate questions (Welner et al, 1999).

When assessing a woman who has an intellectual impairment and where a carer is present, rapport can be established with the woman through: verbal comments and affirmations; eye contact; facial responsiveness; inclusion in explanations and plans; demonstrations using a model; showing tablets and medication; and physical contact where appropriate. If the woman has limited verbal skills, talk to the accompanying person about her, but continue to address her and include her in discussions. Observe her response and use this to guide how much involvement to expect of her in future discussions (Burbidge, 1999).

## Obtain Consent

Medical professionals have a legal and professional responsibility to obtain consent for treatment before treating any patient. As a general rule, adults are considered competent and capable of making decisions regarding their general affairs, including health care (Burbidge 1999). Many people with intellectual impairments can still make informed decisions about their routine care without assistance (Messinger-Rapport et al, 1997). For more complex issues, or when the person cannot make informed decisions, the practitioner should seek consent from an alternative source. In NSW, the Guardianship Tribunal identifies those people from whom substitute consent may be obtained. There are some procedures for which only the Guardianship Tribunal can provide consent. These include tubal ligation; termination of pregnancy; and hysterectomy or endometrial ablation. See Appendix for full details.

### Undertake a Comprehensive Assessment

It has been suggested that the key to general practitioners' success in assessing and treating the sexual health needs of people with disabilities is being comfortable in asking the relevant questions (Szasz, 1991). Women with physical disabilities have suggested that physicians who are comfortable asking questions and are willing to learn from and respect the woman as a partner in the decision making process, are viewed the most positively (Becker et al, 1997). General practitioner comfort in asking the relevant questions is derived from two sources: (1) accepting the woman as a person who happens to have a disability, but whose health and sexual needs, goals and experiences are similar to patients who are not disabled; and (2) using a framework to achieve an objective clinical assessment (Szasz, 1991). The notion of using clinical assessment tools to guide and improve clinical practice for patients with intellectual disabilities has been shown to be effective in Australia. One study that evaluated the Comprehensive Health Assessment Programme (CHAP) noted that general practitioners who used this instrument found it to be a useful tool in the clinical review of patients with intellectual disabilities. The CHAP served as a communication tool and an educative instrument for general practitioners to improve standards of care for people with intellectual disabilities (Lennox et al, 2001).

### Acknowledge the Woman's Expertise in Managing the Disability

Acknowledgment by the general practitioner that the woman with a physical disability is probably the best expert on her own disability needs, contributes greatly to building a smooth and positive interaction. It will also reinforce the woman's sense of control and participation in her health care (Peters, 1982). Most women with physical disabilities know what works best for them and their knowledge can be invaluable during the preparation for the examination and the examination itself (Welner et al, 1999). Use of questions such as, "What would make this easier for you?", "What is the best way for you to transfer to the examination table?" will make the examination easier both for the woman and the general practitioner (Becker et al, 1997; Welner et al, 1999).

### Modify the Communication Style

Women with communication impairments and intellectual disabilities communicate more effectively with communication partners who use clear, short, direct language (Balandin, 2000; Burbidge, 1999). Where there is uncertainty about the woman's communication ability, practitioners should initially proceed on the assumption of competence. Speak directly to the woman and adjust the communication level as necessary (Burbidge, 1999). The following strategies have been proposed for communicating with people who have intellectual or communication difficulties:

- ◆ Be aware that while the woman may have difficulty speaking, she may understand what you say, therefore involve her in the conversation;
- ◆ Take time to get to know how the woman communicates, find out how she indicates 'yes' and 'no', before asking questions;
- ◆ Be aware that communication may take more time than usual, expect a response and wait 10 seconds;
- ◆ Let the woman know that you have understood her, ask her to repeat words you have not understood; never pretend to understand;
- ◆ Make use of the woman's communication aids, such as picture boards, talking machines;
- ◆ If the woman is having difficulty understanding, talk about one idea at time using simple words, simple sentences and simple concepts; adopt the woman's familiar terminology;
- ◆ Supplement communication with signs, gestures and facial expressions to add meaning;
- ◆ Be prepared for silence and pauses in the conversation, learn to be comfortable with them;
- ◆ Use open-ended questions where possible - some women with developmental disabilities may inappropriately say "yes" to closed ended questions;
- ◆ Repetition is useful to reinforce a message; establish the importance of the message and to check that the woman has understood it (Balandin, 2000; Burbidge, 1999).

### Describe the Examination

As with any patient, much anxiety can be allayed with a thorough explanation before the examination. It is important for the general practitioner to describe what will happen during the examination, and why (Peters, 1982). Verbal descriptions of all procedures and instructions are crucial, particularly for women with visual impairments. Women with hearing impairments may require a sign language interpreter to be present to relay questions, explain answers and describe the findings and recommendations. Women with intellectual impairments may benefit from explanations being supplemented by anatomical pictures; simple diagrams or pictures drawn by the practitioner; demonstration of body parts and the planned procedure on the practitioner's body, carer's body or on a model; allowing the woman to handle and explore the equipment; modelling the desired actions; and pointing to the appropriate sign or picture in the person's communication book (Burbidge, 1999).

The importance and value of pre-examination preparation was demonstrated clearly in a single case report by Dahlquist et al (1984). The authors observed that a fourteen year old girl who had previously refused gynaecological examinations, responded effectively to a behavioural approach to facilitate cooperation with the examination. The program involved breaking the gynaecological examination procedure down into

eight discrete steps. Each step was explained and demonstrated, and the girl was rewarded when she cooperated with each step. The results of this behavioural training were generalised to other gynaecological appointments.

Throughout the examination, it is also valuable to reassure a woman with a disability that she will be told before any procedures are started and that she will be kept informed about what is going on. If the woman so desires, allow her to watch the gynaecological examination using a hand mirror. Also encourage the woman to give feedback about possible discomfort, and to ask questions during the examination (Peters, 1982). Maintaining this type of interactive dialogue during the examination ensures that the woman has maximum control over the examination process, thereby increasing participation and cooperation (Welner et al, 1999).

### Ensure the Woman's Safety During the Examination

Once the examination is about to commence the woman's safety must be monitored. Techniques for ensuring safety will be discussed under the heading entitled "General Practitioner Training in Alternate Examination Techniques", however it should be recognised that informing the woman that her safety is being attended to, is an essential component of good general practitioner communication. Reassurance of safety will ease the patient's anxiety during the examination and thereby increase participation. Reduced anxiety enhances muscle relaxation and therefore lessens the impact of spasticity (Welner et al, 1999).

### Give Immediate Feedback about the Examination

As with any patient, it is important to give immediate feedback about the findings of the examination. Phrases such as "your vagina, cervix, uterus and ovaries appear to be normal and healthy' will provide welcome reassurance to a woman undergoing a routine pelvic examination (Peters, 1982).

## 7.2 General Practitioner Training in Alternative Examination Techniques

It has been stated,

*"Providers of screening services should be informed about the health-care needs of women with disabilities, offered techniques for conducting pelvic examinations and mammograms that accommodate such women, and provided information on managing disability-related symptoms that may interfere with examination" (Nosek, 1996).*

There are several strategies that general practitioners can implement to ensure a more successful examination for women with disabilities.

### Allow Extra Time

For a woman with spasticity, muscle relaxation may be enhanced by massage, allowing extra time and giving reassurance to gain the trust and comfort of the patient (Peters, 1982).

### Arrangement of the Examination Room

Arranging the room in such a way as to enhance the woman's comfort will also facilitate a more successful examination. For example ensure that the woman's personal equipment, such as her wheelchair, is left within reach. This will contribute to a sense of safety and physical control during the consultation (Peters, 1982).

### Ensure Safety

Ensuring the woman's safety during the examination process includes using a safe transfer technique to assist the woman onto the examination table, where required (Peters, 1982). This may involve the use of a lifting device, transfer board or utilisation of appropriately trained personnel such as occupational therapist or physiotherapist; use of hand rails on the examination table for women with limited physical control; and stand by physical assistance from appropriately trained personnel (Welner et al, 1999).

### Alternative Examination Positions:

*Pap Smear:* For women with contractures, spasticity or skeletal deformities, the traditional lithotomy position for the Pap test may not be possible for them to assume. The lateral recumbent and knee-chest examination positions may be suitable alternatives. In the lateral recumbent position the client lies on her side with the superior leg brought forward over the lower leg. In the knee-chest position the client lies face down on the examination table with her knees bent forward under her chest. In both these alternative positions the speculum is inserted posteriorly (Peters, 1982).

*Pelvic Manual Examination:* Each individual situation will determine the best approach, however the traditional supine position is generally successful, as less hip abduction is required for this examination than for the Pap smear. While it is more difficult to palpate the ovaries and uterus in the lateral recumbent and knee-chest positions, it is not impossible (Peters, 1982).

### 7.3 Provision of Information to Women with Disabilities about Recommended Preventative Health Care

As previously discussed, women with disabilities lack sufficient information about recommended preventative health care practices. It is therefore recommended that women with disabilities be targeted for preventative health care education (Nosek & Howland, 1997). Such education should focus on an understanding of the risk factors for cancer, as well as the unique factors related to their disability which may delay or prevent the diagnosis of cancer (Nosek & Howland, 1997).

Women with disabilities have suggested the following educational strategies:

- ◆ the establishment of an information network for women with disabilities;
- ◆ developing criteria to assist women to select a suitable health care provider;
- ◆ assertiveness training;
- ◆ modification of the rehabilitation model of health care to teach women with disabilities self-advocacy skills in learning to access reproductive health care;
- ◆ support groups for learning more about sexuality issues;
- ◆ individualised education programs for teenagers with disabilities about sexuality;
- ◆ self-esteem building interventions that focus on building a positive self-image and body awareness;
- ◆ educational events for carers of women with disabilities to inform them of the issues for women with disabilities, including reproductive health issues (Becker et al, 1997).

### 7.4 Environmental Modifications to Improve Accessibility in General Practitioner Premises

The accessibility of the physical environment influences the extent to which individuals with disabilities can participate within their community (Barnes, 1991). Barriers to access and mobility are common, and can be due to factors such as: stairs; door thresholds; and the width of a room (Barnes, 1991). These physical barriers can further handicap a person with a disability. General practitioners' premises are frequently cited as inaccessible by people with disabilities, and are a significant barrier for women with disabilities to obtaining preventative health care examinations (Becker et al, 1997; Iezzoni et al, 2001; Nosek, 1997; Nosek & Howland, 1997; Peters, 1982; Thierry, 2000; Turk et al, 1997; Veltman et al, 2001; Welner, 1998; Welner et al, 1999). In addition, limitations in the physical environment, such as inappropriate equipment, may cause doctors and other professionals to forgo, omit, or not recommend procedures for people with disabilities (The Centre for Universal Design, 2001).

Improvement of the physical environment by the removal of architectural barriers can improve safety and enhance the independence of a person with a disability (Barnes,1991). Modification of the environment can be categorised in three main ways: rearranging the existing environment, such as lowering the reception desk height to enable a person in a wheelchair to speak more easily with the medical receptionist; making additions to the environment, such as providing information in writing as well as verbally; and structurally modifying the environment, such as by the addition of a ramp at the front entrance (Barnes, 1991).

Universal design is a concept, that, when applied to built environments ensures that facilities, products and services are useable by all people, including people with disabilities (The Centre for Universal Design, 2001). Universal design features recommended for health premises include:

- ◆ an accessible parking space close to entrance;
- ◆ an accessible front entrance with a ramp and kerb modified to an appropriate gradient and surface;
- ◆ power door operators at interior and exterior entrances, with weather protection;
- ◆ doors that are wide and easy to open;
- ◆ an accessible route throughout the facility with clear floor space;
- ◆ spaces dispersed in waiting areas where wheelchair users can sit out of traffic lanes but still with people;
- ◆ low counters and service desks, with knee space for wheelchair users;
- ◆ chairs for use by people who cannot stand while transacting business;
- ◆ chairs that can be set at different heights for use by children, adults and older people, some equipped with arm rests for those who need assistance rising to their feet;
- ◆ weighing scales with a hand rail, and scales that allow people to be weighed whilst seated in their wheelchair;
- ◆ motorised height-adjustable examination tables and chairs;
- ◆ mammography machines that can be used with women who need to be seated for the examination;
- ◆ portable amplified communication system with volume control at the service desk and in the treatment area for people who are hard of hearing;
- ◆ audible and visual alarm systems;
- ◆ an accessible toilet and dressing room;
- ◆ TTY telephone facilities for use by people with hearing impairments;
- ◆ print material with large size font;
- ◆ raised lettering and Braille on selected signs and elevator controls; and
- ◆ awareness and sensitivity training for all staff interacting with people with disabilities (The Centre for Universal Design, 2001)

Design requirements for access and mobility to buildings are outlined in standard AS 1428.1 (1993), which is available on the Standards Australia web site, [www.standards.com.au](http://www.standards.com.au). The next section will provide a summary of the key design principles and environmental modifications recommended by Standards Australia that would enable women with disabilities to have better access to general practitioners' offices.

### An Accessible Entrance to the Office

At least one entrance to the general practitioner's office, intended for use by the public, should have a continuous accessible path of travel. This entrance should be identifiable to people with disabilities via an accessibility sign (Standards Australia, 1993). Stairs are potentially hazardous for any user and so a ramp is often the best solution for individuals using wheelchairs, strollers and walking aides, as well as for those with limited mobility (Barnes, 1991). All walkways, ramps and landings must have an unobstructed width of no less than 1000mm. The gradient of these ramps or walkways should be constant and must not exceed 1 in 14. Handrails should be present as they provide safety protection; they should be circular with a diameter of 30mm-50mm. The height of the handrail should not be less than 865mm and not higher than 1000mm (Standards Australia, 1993).

### Accessible Doorways

Every doorway must have a minimum clear opening of 760mm, with 850mm being desirable (Standards Australia, 1993). This width allows people with wheelchairs and walking aides enough room to pass through the doorway. Manoeuvring space is also needed around doors to: open the door; back up while pulling the door open; and to pull the door closed (Barnes, 1991). In general, people who use a wheelchair require a space of 1.5m x 1.5m around a doorway to be able to close the door (Raschko, 1982). Door handles of a horizontal lever design and that require the use of only one hand are the most accessible (Barnes, 1991).

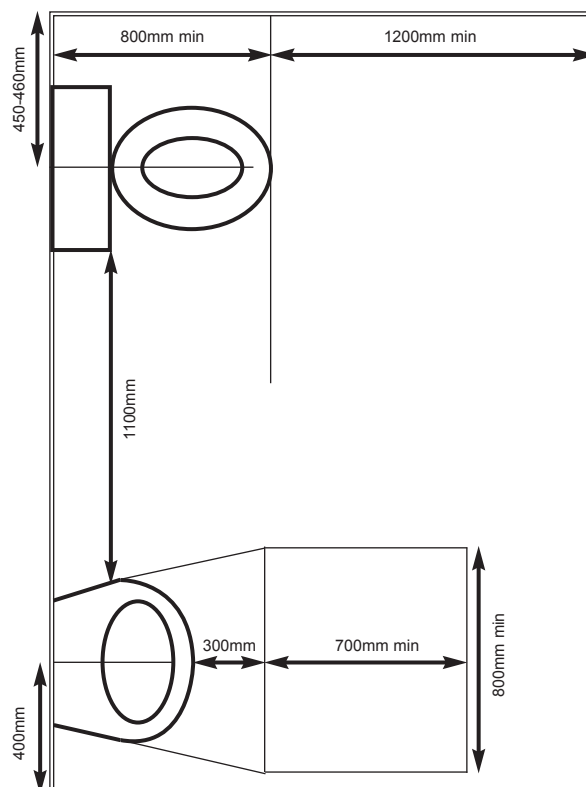
### Floor Surfaces that Enhance Mobility

Hard, level floor surfaces such as ceramic tile, concrete, wood or marble are the easiest surfaces over which to manoeuvre a wheelchair. They can also be beneficial for people with visual impairments because they provide auditory feedback. High gloss finishes to floors are not recommended as they may impede the vision of people with low visual acuity and contribute to falls (Barnes, 1991).

### Accessible Bathrooms

Removing architectural barriers in the bathroom, for people with disabilities, poses one of the greatest design challenges. Standard bathroom entrances, floor plans and fixtures are frequently inaccessible for people who use wheelchairs, walking aides and those with muscle weakness

and in coordination. In general terms, the floor space of the bathroom should be large enough to enable people to enter and exit through the door; transfer onto the toilet; and to provide unobstructed access the sink (Barnes, 1991).



Minimum dimensions have been established by Standards Australia to enable adequate circulation space around the toilet and basin in the bathroom for wheelchair access, these are shown above in Figure 1 (Adapted from Standards Australia building access document 1428.1, 1993).

## 7.5 Accessible Examination Equipment

General practitioners' examination equipment is frequently cited as being inaccessible by women with disabilities seeking preventative health care services. Motorised height-adjustable examination tables and alternate speculums are recommended as strategies for overcoming these barriers (Peters, 1982; Welner, 1998; Welner et al, 1999).

*Motorised height-adjustable examination tables* raise and lower electrically; thereby facilitating safe transfers to the examination couch (Peters, 1982). For women with muscle flaccidity and or spasms, adjustable boots or obstetric stirrups added to the examination table will support the legs during the procedure, thus making the examination easier to conduct (Peters, 1982; Welner, 1998; Welner et al, 1999). In Australia, motorised height-adjustable examination tables are available from various suppliers.

*Alternative speculums* may make the examination easier to carry out. The "Peterson" speculum has narrower blades and may be easier and less painful for use in women with: limited range of motion at the hip joints; postmenopausal vaginal atrophy; nulliparity; or those who are not sexually active. Application of lignocaine gel to the perineal area 2-3 minutes prior to examination can also reduce discomfort. The "Graves" speculum, which is larger in size, may be easier to use with women who have cauda equina lesions and those with lax pelvic structures (Welner et al, 1999).

## 8. CONCLUSION

Women with disabilities have similar or greater risks for cervical and breast cancer as their peers. However, population research across various diagnostic groups has demonstrated that women with disabilities do not receive the same level of preventative health care as the general female population.

The following factors have been identified as contributing to lower screening rates:

- (1) general practitioners have limited knowledge and training about the preventative health care needs of women with disabilities;
- (2) women with disabilities have limited knowledge about their preventative health care needs; and
- (3) general practitioners' premises and examination equipment are frequently inaccessible.

Researchers have recommended the following strategies to increase preventative screening health care practice for women with disabilities:

- (1) general practitioners should receive training in disability awareness and communication skills, especially in the areas of : establishment of rapport; comfort in asking questions; acknowledgment of the woman's expertise; effective communication; describing the examination; ensuring safety; and giving feedback,
- (2) general practitioners should also undergo training in the specialist care of women with disabilities, including the use of suitable examination techniques,
- (3) provision of information to women with disabilities about recommended preventative health care,
- (4) environmental modifications to improve accessibility and
- (5) utilisation of accessible examination equipment.

These recommendations are largely derived from consensus opinion based on studies of attitudes and current practices. What is now required is the implementation of these recommendations and evaluation of their efficacy.

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## APPENDIX

### CONSULTATIVE COMMITTEE

A Consultative Committee was formed whose primary role was to review and advise on the content of the clinical guidelines as well as to disseminate information about the guidelines through their respective organisations. Members of the committee represented a number of key organisations in the disabilities field as well as advocacy groups (see list below).

#### Consultative Committee Members:

- ◆ Dr Trevor Parmenter - Director CDDS, Foundation Professor of developmental disability in the faculty of medicine at the University of Sydney
- ◆ Dr Seeta Durvasula - Medical Practitioner and Lecturer in developmental Disabilities CDDS Sydney University
- ◆ Ms Alix Rainnie - Consumer representative from the Physical Disability Council of NSW
- ◆ Ms Gabrielle Moran - FPA Health representative
- ◆ Dr Katherine Brown - Medical Practitioner with special interest in disabilities. Illawarra Sexual Health
- ◆ Dr Elizabeth Hindmarsh - Royal Australian College of General Practitioners
- ◆ Dr Gerry Wain - Director of the NSW Cervical Screening Program, Director of Gyne Oncology Unit at Westmead Hospital
- ◆ Ms Kim Hobbs - Social Worker Gyne Oncology Unit, Westmead Hospital
- ◆ Ms Jayne Ross - Manager, NSW Cervical Screening Program

#### Secretariat:

- ◆ Ms Raquel Clarke - Research Fellow, CDDS
- ◆ Ms Iona Novak - Research Fellow, CDDS
- ◆ Ms Amanda Niciak- Manager - Health Promotion and Communication, NSW Cervical Screening Program
- ◆ Ms Dina Retter - Project Officer, NSW Cervical Screening Program
- ◆ Ms Georgette Roumanos - Administration Assistant, NSW Cervical Screening Program

### FURTHER CONSULTATION

Draft Guidelines were sent to the following organisations for distribution and comment.

- ◆ Council for Intellectual Disability
- ◆ Association of Doctors In Developmental Disability
- ◆ Women With Disabilities Australia (WWDA)
- ◆ People With Disabilities (NSW) Inc.

The Guidelines were also discussed at the NSW Cervical Screening Program's General Practitioner and Women's Task Forces (membership and organisation / group representing below):

#### GP Task Force

- ◆ Dr Elizabeth Hindmarsh (Chair), Alliance of NSW Divisions
- ◆ Dr David Sanders, Rural Doctors Association Hunter Rural Division of General Practice
- ◆ Dr David Tillet, Border Division of General Practice
- ◆ Dr Con Paleologos, Western Sydney Division of General Practice
- ◆ Dr Cathy O'Hearn, South Eastern Sydney Division of General Practice
- ◆ Dr Karen Ramsay, Rural Doctors Association
- ◆ Dr Gerry Wain, Clinical Oncological Society of Australia, Australian Society for Colposcopy and Cervical Pathology, International Gynaecological Cancer Society
- ◆ Dr Trish Vezgoff, Consumer representative

#### Women's Task Force

- ◆ Dr Edith Weisberg (Chair), FPA Health
- ◆ Ms Trude Kallir, Older Women's Network
- ◆ Ms Anne Connolly, Women's Health Services Policy Branch, Department of Health
- ◆ Ms Cailya Booth, NSW Pap Test Register
- ◆ Dr Trish Vezgoff, Consumer representative
- ◆ Ms Ilona Lee, Multicultural Health Services
- ◆ Ms Sue Burke, Women's Health Service, Mid Western Area Health Service
- ◆ Ms Barbara Kendrick, NSW Country Women's Association
- ◆ Ms Lola McNaughton, National Health and Medical Research Council
- ◆ Ms Jayne Ross, Program Manager, NSW Cervical Screening Program





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