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Can Women with Learning Disabilities Access Good Health Care? A Case Study of Cervical Screening

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Introduction

Women are frequent users of health services, not only for themselves, but also for those for whom they care – children, dependent adults and older people. Their ability to access good and appropriate health care, both in their own right and as caregivers is, therefore, of paramount importance (Pavalko, 2000). Some women are more skilled and able to access appropriate care. For example, individuals in higher socio-economic groups do better than those in lower socio-economic groups in accessing health care (Townsend and Davidson, 1988), and in their survival of cancer and heart disease (Phipps, 1999). Reasons for inequalities are many, ranging from communication skills through to affordability (Northam, 1996). Many studies of take-up of health care such as immunization, screening and health clinics, conclude that poor and less well-educated people are less likely to take up services, or to use them appropriately. This is a situation which is both costly and may contribute to some diseases re-establishing themselves in vulnerable and socially excluded groups without early interventions. There are indications of a continuing and ‘growing division between the haves and have nots in our society’ (Millman, 1993: p. 4).

In this chapter, I suggest that even established prevention services such as cervical screening are denied to some groups of women by a complex set of barriers. The chapter will explore both access and barriers to health care based on findings from a qualitative study on health access for women with learning disabilities which focused on cervical
screening (Nightingale, 1997). The data show how these issues may affect whether many groups of women understand or are even offered the cervical screening service.

Cervical cancer

Cervical cancer occurs at the neck of the womb, where the vaginal canal and uterus meet. There are two forms of cervical cancer, adenocarcinoma and squamous cell carcinoma. Adenocarcinoma is a rarer form, but it can occur in any woman whether she has been sexually active or not. The squamous variety accounts for 90 per cent of cervical cancers and is predominately linked with sexual activity, including early age of first sexual intercourse, number of sexual partners and after contracting sexually transmitted diseases, particularly vaginal warts or human papilloma virus (Grubb, 1986; Mihill, 1990; Singer and Yule, 1984).

In the United Kingdom, 2,000 women die each year from cervical cancer. Of these, 88 are thought to be preventable deaths had the cancer or pre-cancerous signs been detected earlier by screening (Smith and Jackson, 1988). Pre-cancerous changes to the cervix can be successfully treated, halting the progression of the condition. Detection by cervical screening is a relatively simple procedure undertaken in most general practice surgeries, family planning and Well Woman Clinics, saving the lives of 800–1,000 women annually (Boseley, 1999). The smear test, which involves scraping a sample of endo-cervical cells from the cervix with a cervical spatula or brush, is usually painless, though many women may experience discomfort and embarrassment. As Harris notes (Chapter 1, this volume), it is an invasive and personal procedure, and gives rise to concerns from the screeners themselves (Nightingale, 1997), yet such discomfort is rarely acknowledged even within the health education and promotion literature.

Learning disability

Women with learning disabilities are as eligible for screening as other women. However, they have a label which is broad, confusing and easily misunderstood. Some may have severe learning disabilities, leaving them with poor receptive and expressive communication as well as poor cognitive processes, while others live independent lives. Some will have been sexually active, either by choice or through abuse