IMPROVING EQUALITY OF ACCESS TO CERVICAL SCREENING

Karen Gribben and Michelle Bell examine the literature on why women with a learning disability are not attending for smear tests and missing out on this potentially life-saving service

Summary

People with learning disabilities have unmet health needs and lower uptake of services and screening. There is evidence that women with learning disabilities do not get the same opportunity as other women to access cervical screening. The main issues identified in this literature review were barriers to accessing services, which include attitudes and training of professionals, carers and service users, inadequate resources and invitation letters, and consent.

Recommendations for future practice include partnership working to raise awareness of professionals, service users, parents and carers; identifying relevant resources for service users and professionals; and the need for guidance to be developed for those who are working with people with learning disabilities.

Keywords

Access to health services, cervical screening, learning disabilities, sexual health

Discrimination

Watts (2008) further stated that people with learning disabilities are often discriminated against when accessing mainstream services, including cervical screening. Statistics show that between 3 and 17 per cent of women with learning disabilities access cervical screening services compared with 85 per cent of the general population (Scottish Executive 2004).
Having a smear test
In Scotland screening is offered to every woman from the age of 20 until her 61st birthday and the NHS Cancer Screening Programme recommends that age and the absence of a cervix are the only reasons for stopping screening (Reynolds et al 2008). Wood and Douglas (2007) stated that although women with learning disabilities appear to be at lower risk of cervical cancer than the general population, their risk is not negligible.

Mortality rates
Recent figures of the incidence of cervical cancer underline the need for all women to take up screening opportunities. In 2005, 2,803 new cases of cervical cancer were diagnosed in the UK, making it the 12th most common cancer in women, accounting for about 2 per cent of all female cancers (Cancer Research UK 2009a). Cancer mortality rates in 2007 were nearly 70 per cent lower at 2.4 per cent per 100,000 females, than they were in 1977, at 7.4 per cent per 100,000 females (Cancer Research UK 2009a). In 2007, there were 941 deaths due to cervical cancer in the UK, of which 105 were in Scotland (Cancer Research UK 2009b). In Scotland in 2000 there were 305 cases of cervical cancer in all ages compared with 291 cases in 2006 (ISD Scotland 2009).

Cervical cancer mortality rates generally increase with age, with the largest number of deaths occurring in women in their seventies. The fall in cervical cancer morbidity and mortality rates is attributed to increased screening activity (Cancer Research UK 2009a). It is widely accepted that invasive carcinoma of the cervix is preceded by pre-malignant lesions for which early treatment is effective (Cancer Research UK 2009c).

Human papilloma virus (HPV) can affect the skin and mucus membranes that line parts of the body. There are more than 100 different types of HPV, some of which are sexually transmitted. Some sexually transmitted HPV types, known as ‘high risk HPV type’ can cause changes in cells of the cervix. These changed cells have an increased risk of becoming malignant (Cancer Research UK 2009d).

Although there are many different types of genital HPV, it is only types 16, 18 and 31 that can cause cervical cancer. Women with learning disabilities should not be assumed to be sexually inactive and therefore not at risk of HPV (Broughton and Thomson 2000, Reynolds and Stanistreet 2008). Additional risk factors for cervical cancer include the use of oral contraceptives, previous childbirth, sexually transmitted infections, smoking and multiple partners (Broughton and Thomson 2000, Reynolds et al 2008, Watts 2008).

One of the main aims of Respect and Responsibility, the sexual health strategy for Scotland (Scottish Executive 2005), is supporting those who face discrimination because of their life circumstances, sexual orientation or disability to acquire and maintain the knowledge, skills and values necessary for positive sexual health and wellbeing, such as women with learning disabilities.

The strategy also stated that every person should have a choice when accessing sexual health services. Service provision should be based on the principle of providing services that are as local as possible and as specialised as necessary. Realising this aim for women with learning disabilities requires an understanding of the barriers they face in accessing cervical screening and how these can be overcome.

Literature search
The following databases were searched for journal articles and research papers to obtain literature on cervical screening of women with learning disabilities: the Cumulative Index of Nursing and Allied Health literature (CINAHL), British Nursing Index (BNI) and Medline. Abstracts were reviewed to assess whether literature was pertinent to the topic. The search was limited to English language publications between 1998 and 2009, to get up-to-date information on the subject. Keywords used were: sexual health, cervical screening, learning disabilities, intellectual disability, mental retardation, and sexual health education. It was found that there was a wide range of literature available on the topic. Relevant websites were also searched visually.

Barriers to screening
It is important for all women to be screened to reduce mortality rates, but there are many barriers for women with learning disabilities to access this service. Those cited by health workers include: communication difficulties, attitudes of carers and staff, difficulties in obtaining consent, lack of accessible information, inflexible appointment times, poor liaison with specialist teams, access to GP services, and inappropriate resources (Stein and Allen 1999, Broughton and Thomson 2000, Kopac 2002, Biswas et al 2005, Lehmann 2005, Royal College of Nursing 2006, Wood and Douglas 2007, Ramessur-Marsden et al 2008, Watts 2008).

The barriers can be grouped under four headings: attitudes and training; resources and invitation letters; consent; and partnership working.

Attitudes and training The evidence suggests that cervical screening is rarely offered to women with
learning disabilities, yet it should not be assumed that they are not sexually active (Stein and Allen 1999, Watts 2008). They are entitled to the same services as everyone else. Many studies suggest that there is inadequate training in relation to sexual health and learning disabilities for professionals, parents and carers, and service users (Stein and Allen 1999, Broughton and Thomson 2000, Broughton 2002, Wood and Douglas 2007). Several authors conclude that professionals need to be adequately trained in communication skills and understanding the complex needs of women with learning disabilities to be able to provide screening appropriately (Stein and Allen 1999, Broughton 2002, Wood and Douglas 2007). Broughton and Thomson (2000) stated that staff who carry out the screening require training on the needs and problems of people with learning disabilities.

Learning disability nurses are well placed to provide training because they have specialist skills, training, knowledge and the expertise to advise and support primary care professionals (Broughton 2002). Community learning disability nurses could provide the training in collaboration with specialist workers in sexual health (Watts 2008). Wood and Douglas (2007) stated that joint working is patchy and that there is little enthusiasm in primary care for formalising joint working arrangements. Broughton and Thomson (2000) agreed that specialist learning disability nurses need to develop closer links with primary care staff. They suggested that the training could lead to an increased awareness of the importance of allowing extra preparation time and to repeat information provided to clients.

Reynolds et al (2008) performed a retrospective cohort study to ascertain whether women with learning disabilities are more likely to be excluded from a cervical screening programme than women without learning disabilities. They found that being coded as having learning disabilities is not the only reason for stopping and/or not screening; a small number of women will not consider undergoing cervical screening and will become distressed if the procedure is attempted.

Reynolds et al (2008) recommended those conducting cervical screening needed training in providing screening for women with learning disabilities and when it was appropriate not to screen. A previous study (Reynolds and Stanistreet 2008) found that GPs considered screening to be unnecessary for women with learning disabilities.

Wood and Douglas (2007) highlighted the need to address the attitudes and experiences of women and their carers. Staff and carers must acknowledge the rights of women with learning disabilities to access services (Watts 2008). Reynolds and Stanistreet (2008) suggested that people with learning disabilities and their carers often have low expectations of their own health and the services they receive, sometimes to such an extent that they tolerate poor health. Reynolds and Stanistreet (2008) made no recommendation for training for carers and service users, but they did report that women with learning disabilities can feel that staff lack understanding of their disability and often focus on this, rather than on the immediate health issue (Reynolds and Stanistreet 2008).

Many authors agree that the attitudes of both the carer and clinician can influence whether women with learning disabilities attend for cervical screening (Kopac 2002, Biswas et al 2005, RCN 2006). Kopac (2002) carried out a randomised survey of 727 nurses to obtain their perspective on the accessibility of gynaecological and reproductive services for people with learning disabilities, and found that participants noted a lack of knowledge and empathy on the part of the healthcare provider. They also noted that carers and clinicians considered cervical screening was not appropriate for people with a learning disability because they were not currently, or had never been, sexually active.

In addition, Kopac (2002) noted that screening, testing and treatment for sexually transmitted infections and HIV/AIDS are not recognised as important for adolescents and women with learning disabilities. Ramessur-Marsden et al (2008) described an initiative to produce health education packages for community learning disability teams to support people with learning disabilities to access screening. They found that there was a misconception that cervical screening is not necessary for women with learning disabilities.

**Resources and invitation letters** The way women are invited to attend for cervical screening may be a reason for low uptake (Broughton 2002, Wood and Douglas 2007, Watts 2008). Women and parents or carers need more information about the importance of the procedure, as well as encouragement and support to use cervical services (Broughton and Thomson 2000). Women in Scotland are invited to attend for smears by the Scottish Cervical Call-Recall System (SCCRS). In 2007 this replaced previous systems for cervical screening call and
recall, including those used in general practice. In June 2000 a report was published on a quality improvement review of cervical screening call-recall arrangements in Scotland. This highlighted the need for a major redevelopment of the current information technology systems for the management of the cervical call-recall system (NHS Scotland 2009). It was this report that the SCCRS project came from.

The SCCRS application, accessible by more than 12,000 users over the secure NHS network, offers a single Scotland-wide database to support the Scottish Cervical Screening Programme. It is used by a wide range of NHS staff including GPs, nurses, family planning consultants, colposcopists, gynaecologists, laboratory scientists, cytopathologists, consultants in public health medicine and call/recall office staff (NHS Scotland 2009). SCCRS has introduced electronic cervical screening requesting and results reporting. Significant benefits are the instant availability of clinical information at the point of patient care and notification of cervical screening results to women (NHS Scotland 2009).

Evidence shows that in Scotland all women, including those with learning disabilities, receive a mail prompt letter to attend for cervical screening (Watts 2008). If they do not attend, two reminders are sent. Women who have had abnormal results in the past are sent the prompt letter and three reminders. Watts (2008) suggested that this method of invitation could be a barrier because of low literacy skills among women with learning disabilities and a lack of understanding of the letter. Broughton (2002) stated that the issue is wider than just being able to read and understand the invitation letters, but may be relevant to non-attendance. Watts (2008) added that the invitation may not be passed to the women by their parents or carers because they deem attendance to be unnecessary.

Watts (2008) also suggested that a woman with learning disabilities who also has reading difficulties will be unlikely to understand the results letter which contains medical jargon such as ‘abnormal’ or ‘dyskaryosis’. Broughton (2002) stated that the health promotion leaflets on cervical screening may be difficult to understand, and recommended that leaflets and invitations to attend for screening should use appropriate language and text. Also, using pictures, videotapes, audiotapes, and enabling the person to have a preparatory visit to a screening clinic, can improve understanding.

Reynolds et al (2008) carried out a retrospective cohort study using case control methods in women with learning disabilities and access to cervical screening. They found an increased likelihood that their screening had ceased or that they were not receiving screening, indicating that many improvements are needed. They added that it may be necessary to improve invitations by developing tailored letters or processes by which the learning disability teams could be notified that a screening invitation has been sent (Reynolds et al 2008).

A research project undertaken in Edinburgh found that women’s literacy skills affect how they understand the invitation letter, and suggested that some women relied on others to explain the contents of the letter (NHS Lothian 2006). Support to read and understand the letter was provided through informal networks, including family, friends and support workers (NHS Lothian 2006). The report, Women with Learning Disabilities and Carers’ Experiences and Views of Cervical Screening (NHS Lothian 2006), also highlighted carers’ views, which suggested that invitations should be personalised.

The report suggested providing a pictorial leaflet in a range of formats for women and carers, which describes eligibility for cervical screening and risk factors for cervical cancer. This leaflet could be used in practices to support health professionals in their discussions with women about screening. The report also suggested that practices should routinely use the leaflet for clients with learning disabilities. Standard unadapted invitations for cervical screening should not arrive ‘out of the blue’ and should be accompanied by the offer of a wider discussion about cervical screening (NHS Lothian 2006).

Consent Factors that may limit access to cervical screening include perceived difficulty in obtaining consent for screening (Stein and Allen 1999, Watts 2008). Broughton and Thomson (2000) suggested that women with learning disabilities are less likely to have a test because they are deemed unable to give consent. Broughton (2002) stated that a person’s capacity to give informed consent is pivotal in the decision making about healthcare interventions.

Current thinking is to encourage people with learning disabilities to make decisions for which they are deemed capable. Broughton (2002) stated that a person’s capacity to give informed consent is essential to the decision-making process; adding that a more involved approach is preferable to a non-participatory one. This approach focuses on the individual being able to understand the function of the procedure to be able to make a decision whether or not to have the treatment. Broughton and Thomson (2000) suggested that the capacity of women with learning disabilities to give informed consent is likely to be influenced by the use of an understandable format for providing information.
Wood and Douglas (2007) carried out a study that aimed to evaluate current practice in, and to explore primary care professionals’ views about, providing cervical screening to women with learning disabilities in two areas of Edinburgh. Wood and Douglas (2007) suggested that although most women with learning disabilities can give and withhold consent to cervical screening, a small minority cannot because of severe disability. Research in Edinburgh suggested health professionals require a guide on good practice in consent to cervical screening, including checking understanding of cervical screening (NHS Lothian 2006).

**Partnership working** Wood and Douglas (2007) performed a study that aimed to evaluate practice in, and to explore primary care professionals’ views of, providing cervical screening to women with learning disabilities in two areas in Edinburgh. A respondent commented: ‘someone should have the ability to refer certain patients on to some form of specialist resource or service’, either specialist cervical screening nurses in primary care or specialist clinics in family planning clinics. However, the focus of policy and overall service development is promoting access to mainstream services; rather than creating specialist learning disabilities screening services, there should be a focus on improving the skills in mainstream ones. This is supportive of Promoting Health, Supporting Inclusion (Scottish Executive 2002). Wood and Douglas (2007) emphasised partnership working with clients, parents, carers and professionals, and suggested that more innovative ways to encourage joint working between community learning disability teams, specialist services and primary care should be sought.

Wood and Douglas (2007) suggested that guidance on cervical screening be developed for those who are working with people with learning disabilities. The NHS Cancer Screening Programme has developed guidance to ensure equal access to breast and cervical screening for disabled women (NHS Cancer Screening Programmes 2006); the RCN has also produced guidance for nurses in meeting the health needs of people with learning disabilities (RCN 2006). Wood and Douglas (2007) stated that the SCCR S should ensure that the primary care team retains the option of supplementing centrally processed screening invitations and results letters to meet the needs of patients with learning disabilities. Anecdotal evidence suggests this may be hard to do, and it should perhaps be implemented on a case-by-case basis, because the SCCR S system is national which would be more difficult to change. When a woman with learning disabilities receives the invitation, joint working with community learning disability teams and specialist services could take place, including education of clients and carers, and adequate preparation, such as using simplified leaflets to help explain the procedure.

Developing closer links with primary care and specialist services can be a means of improving this preparation. Broughton (2002) emphasised the importance of using language that the woman understands, and of providing opportunities for the patient to familiarise herself with the surroundings in which the test will take place, and the staff who will perform the procedure. Improvements can be made by working in partnership and ensuring good up-to-date practice (Watts 2008). However, Wicks (2007) argued that, although it is possible to improve professionals’ skills by providing access to relevant information and training, they also need to consider appointment times and preparatory work.

Health outcomes also depend on the knowledge and beliefs of people with learning disabilities – clients have to want to undergo screening – therefore more education of clients and carers is needed. This may entail further partnership working to deliver appropriate health promotion messages in the community.

**Recommendations**

In Ayrshire and Arran a sexual health nurse for learning disabilities has been appointed. This is in keeping with Ayrshire and Arran’s Strategy to Improve Sexual Health Draft Policy 2009 to reduce inequalities in health. Our recommendations, as a result of the literature review, are as follows:

- Women should not be excluded from screening services due to assumptions about their disability, sex lives or perceived difficulties in obtaining consent.
- Joint working should be established and maintained with all key partners such as service users, parents, carers and professionals.
- Awareness needs to be increased about the issues surrounding cervical screening and women with a learning disability by providing training to nurses and/or GPs on delivering this service.
- Relevant resources for service users need to be identified and, if necessary, resources need to be developed and produced in partnership with service users and carers, to assist women’s understanding of cervical screening, invitation letters and results.
- A guidance document should be developed for those working with people with learning disabilities in relation to cervical screening and sexual health.
Ways to improve the understanding of women with learning disabilities of invitations for screening need to be identified. This could be a role for primary care which would be triggered on receipt of the monthly routine call list from SCCRS.

Conclusion

This article has reviewed the literature about cervical screening and women with learning disabilities. It has identified that these women should be offered screening despite the many barriers and should not be excluded because of assumptions about their disability, sex lives or perceived difficulties in obtaining consent. The review has shown how the barriers could be addressed by providing recommendations for future practice. As a result of this review the authors intend to develop a pilot project in selected surgeries in East Ayrshire to put the recommendations into place and ensure access to cervical screening for women with learning disabilities locally.

The recommendations of this literature review support one of the main aims from Respect and Responsibility: Strategy and Action Plan for Improving Sexual Health (Scottish Executive 2005), which is to support everyone in Scotland, including those who face discrimination due to their life circumstances or their gender, race or ethnicity, religion or faith, sexual orientation, disability or age, to acquire and maintain the knowledge, skills and values necessary for good sexual health and wellbeing. The recommendations also support one of the main recommendations and actions from Ayrshire and Arran’s Strategy to Improve the Health of Children with Learning Difficulties and Adults with a Learning Disability 2009, which is to improve health, wellbeing and social inclusion, and to reduce health inequalities. The strategy also recommends that awareness raising and training on diversity issues should be provided for staff who deliver services to people with learning disabilities.

In addition, the recommendations support one of the indicators of inequalities in health in Ayrshire and Arran’s new sexual health draft policy 2009, which is to improve access to sexual health services for people with learning disabilities, by working with service users, professionals, carers and parents. In conclusion, there is still a need for further research and practice development in relation to cervical screening and women with learning disabilities.

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References


