SCREENING SUPPORT FOR WOMEN WITH LEARNING DISABILITIES

INTRODUCTION
The Mental Capacity Act 2005 means screening services and learning disability teams have a duty to provide support to enable women to make decisions about screening. There should also be clear guidance for services concerning best-interest decisions regarding screening. This project was a joint exercise with Screening Services, Velindre NHS Trust and the community learning disability teams from North East Wales NHS Trust.

IMPROVING COMMUNICATION
Breast Test Wales and Cervical Screening Wales carried out a joint health promotion initiative in North Wales. A workshop held with women with varying degrees of learning disability found a wide range of comprehension levels about breast and cervical screening. Terms and topics that healthcare professionals assume are understood by most women – such as ‘scan’ or ‘test’ – are often poorly understood by those with a learning disability.

Finding ways to represent concepts that, for many people, are straightforward is a challenging process and one that requires staff to think more creatively and with more empathy.

All staff groups need to appreciate the communication and cognitive difficulties involved when supporting people with learning disabilities and view solutions directly from service users’ perspectives.

The model used in the health education package could be applied to any service, making the communication of specific information more available.

 implied for practice

Toolkit
Each participating learning disability team was issued with a cervical screening toolkit, which allowed nurses to demonstrate the cervical screening process or smear test in a more visual way, thus reinforcing learning. Items such as a demonstration cervix, speculum, samplers and smear test request form were included.

Care pathways
These were developed to help teams support women through the learning and decision-making processes for screening. They also offer guidance on best practice for teams if the woman is unable to consent.
BACKGROUND

- People with learning disabilities are more likely to have health difficulties than the general population but less likely to access health support and screening (Lennox et al, 2001; Powrie, 2001).
- The Welsh Assembly Government (2004) referred to the difficulties faced by people with learning disabilities in accessing health services, despite their right to the same services as others.
- The Department of Health’s (2001) white paper *Valuing People* said: ‘Few people with learning disabilities access health screening services with uptake rates for breast and cervical screening being especially poor.’

Checklists
These enable nurses to see at a glance if they have covered key aspects needed for an informed decision, and to check how much information the client can retain. If further explanation is needed, the relevant section of the pack can be looked at again. Checklists can be added to clients’ files.

PILOT
Screening Services carried out a pilot study to determine the effectiveness of the package. It held a training event in summer 2006 to launch the packs. A representative from each community learning disability team in North Wales was invited to attend.

The session included explanations of:
- The project and the background to its development;
- How the pack was to be used;
- The intended evaluation process.

After distributing the packs to participating teams, it was agreed that the pilot should be conducted over six months in North Wales. During the pilot, learning disability nurses were to use the packs in individual and group-work settings with clients. All aspects of the package were to be used for the pilot.

Evaluation
During the pilot phase the project team designed comprehensive questionnaires in order to collect qualitative data.

Two questionnaires were developed, one for learning disability healthcare professionals and one for service users to complete. This enabled us to collect feedback from two different perspectives.

In December 2006, we distributed questionnaires to the teams involved. Following this, the project team made appointments to interview those who had agreed to take part. The aim was to gain as much qualitative evidence as possible to support this project. It also allowed us to identify the pack’s shortfalls and address any modifications.

Following the interviews, we were able to:
- Identify common themes from learning disability teams’ perspectives;
- Assess the design and sequencing of the packs;
- Highlight areas needing modification;
- Broaden areas that were requiring additional information.

The questionnaire asked those taking part to score each section of the package. The scoring system involved a linear scale that asked participants to rate the pack from 1 to 5, with 1 being poor and 5 being excellent. Overall, the package scored very well.

The pilot led to a range of recommendations including making the package available as a web-based resource, improving picture quality, planning structured training for learning disability teams and holding service-user events to promote the packs.

FURTHER WORK
The *Having a Breast Test and Having a Smear Test* packs are easily available to local teams and the public on the Screening Services’ website at www.screeningservices.org. They can be downloaded in PowerPoint or PDF format.

This allows community learning disability teams to use the packs, whether in a group setting or on an individual basis. Cervical toolkits are available on request to all learning disability teams in Wales.

A training plan is also now in place for all learning disability teams in Wales. This involves recruiting members from community learning disability teams to become a screening link person. The aim of this is to develop and nurture a link between their teams and Screening Services. Training has been completed in North Wales and is now being implemented in other divisions.

The health minister for Wales, Edwina Hart, launched the teaching packs at a one-day service-user conference held in North Wales in May 2008. The conference was specifically for women with a learning disability and gave them a chance to attend a fun, informal day providing information on a range of health-related topics.

CONCLUSION
The health education package allows greater understanding and awareness of breast and cervical issues from a patient-centred approach. The model can be adapted to fit alternative screening programmes and can be used with people with learning disabilities or other groups with special needs.

REFERENCES


