Train the Trainers – Learning Disabilities Pilot

Executive summary

This summary provides an overview of results from a pilot evaluation examining the outcomes and impact of the Train the Trainers – Learning Disabilities Pilot, delivered in November 2010.

Nearly 50,000 people a year are diagnosed with breast cancer in the UK. The sooner the diagnosis is made, the better the chances of successful treatment and improved outcomes. There are a number of communities that are particularly vulnerable as we know they are likely to present later with symptoms. The Breast Health Promotion programme directly meets one of the key areas of impact of the Breast Cancer Care Vision 2020\(^1\) strategic document. It aims to promote early detection and presentation and encourage screening to women known to be at high risk of breast cancer, delayed presentation or low uptake of screening.

Uptake of breast cancer screening is lower in women with learning disabilities than in the general population (DoH White Paper, 2001). Identified barriers to attending breast cancer screening among women with learning disabilities included methods of referral, poor registration rate with GPs, poor literacy skills, ill health, transport issues, general fears about the healthcare system, and attitudes (perceived or not) from healthcare professionals\(^2\). The Breast Cancer Care Extending Reach project (December 2005) led to the creation of an information pack specifically aimed at people supporting women with learning disabilities. Simultaneously, Breast Cancer Care was developing its breast health promotion services, with the formation of the Train the Trainers programme in 2008 – a programme providing training to local health promotion/community workers in breast cancer awareness messages. In this context a specialist Learning Disability Train the Trainer course targeting carers and supporters of people with learning disabilities, as a key group supporting women with learning disabilities on a continuing basis, was developed.

The Train the Trainers – Learning Disabilities (TtT LD) course was piloted in partnership with Birmingham PCT aiming at people who support women with mild to moderate learning disabilities and professionals facilitating health education to this client group.

Methods and sample

This pilot was evaluated using a mixed method approach, combining administration of a shortened version of the Breast–CAM before and four weeks after the course, immediate feedback forms and semi-structured qualitative interviews four weeks after attendance to find out about their experiences in delivering breast awareness messages.

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The sample included all trainees who took part to the pilot (N=6). Informed consent was obtained from trainees when they registered for the course, with the option to opt out from the evaluation study.

Table 1: Number of participants engaged during the evaluation process

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<tr>
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<th>Number of participants</th>
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<tbody>
<tr>
<td>Pre-questionnaire</td>
<td>N=6 (100%)</td>
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<tr>
<td>Immediate feedback</td>
<td>N=6 (100%)</td>
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<tr>
<td>Post-questionnaire (4-6 weeks)</td>
<td>N=4 (67%)</td>
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<td>Qualitative interviews (4-6 weeks)</td>
<td>N=5 (83%)</td>
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Findings

‘You have got to know the background information to be able to tell it to other people. And obviously showing us how to do it was really good and it gave us ideas of how to relate it to people with learning disabilities.’

Knowledge and behaviour

Following attendance to the course:
• confidence to detect breast change increased, with improved level of signs and symptoms recognition
• levels of knowledge around lifetime and age-related risks remained unchanged
• there was a positive effect on knowledge of the breast screening programme, but a lessening confidence in how to address the barriers to access
• the course positively impacted on participants’ attitude, behaviour and perceptions of breast awareness

Confidence to deliver breast cancer awareness messages

“I would have said things like ‘make sure you go to your doctors for a check’, or ‘have you been for a check’, but to actually go to the next step of showing them how to check, I wouldn’t have done that [before attending the course]”

• Participants reported higher levels of confidence in being able to tell other women about their risk of developing breast cancer, explaining the difference between breast awareness and self examination and describing how the NHS Screening programme works.
• However, participants reported reduced levels of confidence in being able to encourage women to visit their GP and discussing the advantages of early treatment\(^3\).
• Increase in confidence in delivering the breast cancer awareness message was greater for participants who had delivered breast awareness sessions in the first month post-attendance.

\(^3\)Recommendations for review of these areas have been made to the operational team, prior to the rolling out phase.
Delivering breast awareness messages and impact on end user

**Figure 2: A trainee’s story of change**

<table>
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<tr>
<th>Self-awareness</th>
<th>Breast Self Examination vs Breast Awareness?</th>
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<td>‘I am aware of breast cancer because I am a woman, but it is not at the forefront of my mind... it has helped concrete those thoughts, those general awarenesses you have as a woman really.’</td>
<td>‘[The silicone breasts] weren’t brilliant [...] we did have problems trying to find the lumps in the models... They did not realise and neither did I – I’ve got to be honest – how far you have to feel.’</td>
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<tr>
<th>Dissemination</th>
<th>Impact on client group</th>
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<td>‘I’ve sort of shied away from it in the past because [...] I would hate to think I was conveying the wrong message or not conveying it properly... but I don’t feel like that anymore.’</td>
<td>‘We were talking about the benefit of well fitting bras [...] As a result the manager of the wellbeing centre took all the women to M&amp;S to get them properly measured.’</td>
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</tbody>
</table>
The impact on knowledge and behaviour impacted on trainees’ self awareness and their understanding of the breast awareness concept – which they recognised to be more adapted to the needs of women with learning disabilities. As a result of this, they shifted their practice towards more practical activities when disseminating the message. The impact on their client group was immediate and case studies demonstrated direct behaviour change.

**Lessons learnt**

- Successful partnership in developing support services between the National Health Service and the Third Sector through knowledge and expertise transfer.

- Need for further skill development in understanding the practice implications of the Mental Capacity Act / Adults with Incapacity (Scotland) Act.

- Marketing activities to concentrate on professionals who have a remit to deliver the learning disability wellbeing agenda and whose remit is to proactively engage with this client group.

- TtT LD to be offered as a bolt-on training to specialist and community nurses, who have undertaken the generalist TtT course to improve their confidence to address these specific situations.

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Participant A (Health Facilitator) has used the learning disability packs to raise awareness of breast health with carers to demonstrate the benefit of breast awareness to themselves and to the person they are caring for. The packs were sent through a targeted mass mailing along with a letter highlighted the need to act on NHS Screening invitation letters. She is now going through the packs with carers so they can use this resource at home with the women they are caring for.

Participant A (Health Facilitator) used the opportunity of health action plans to deliver message about breast awareness to her client. She explained to the young woman the need to be breast aware by drawing pictures, showing how to look and feel and what to do if any out-of-ordinary changes were observed. Following this, the young woman started to check herself at home and found a lump. She went straight away to the doctor to get it checked.

Participant D (Health Facilitator) delivered two group sessions in a women well being centre for people with mental health problems. She used the silicone breast to demonstrate the need for correct bra fitting to improve your breast health outcomes (instead of using them to seek lumps). The message impressed as much onto participants as it did onto the centre workers, who at the end of the session, got all the women to a Marks & Spencer shop for bra fitting. Participant D was asked to facilitate regular sessions throughout the year.