Train the Trainer: Learning Disabilities course pilot

Evaluation report
May 2011
Contents

1 Introduction and background 3
   1.1 The Train the Trainer programme 3
   1.2 Why a Learning Disabilities pilot? 3
   1.3 Train the Trainer: Learning Disabilities course pilot – aims and objectives 4

2 The evaluation 5
   2.1 Aims 5
   2.2 Methods 5
   2.3 Sample 5
   2.4 Outline of report 6

3 The pilot: planning, delivery and feedback 6
   3.1 Trainees’ characteristics 6
   3.2 Trainees’ expectations 6
   3.3 The training day 6
   3.4 Trainees’ feedback 8
   3.5 Toolkits and resource packs
   3.6 Planning, delivery and feedback: lessons and recommendations 9

4 Outcomes and impact 11
   4.1 Levels of breast awareness 11
   4.2 The trainees’ journey: the process 16

5 Summary 19

6 Recommendations 20
1 Introduction and background

1.1 The Train the Trainer programme

The breath health promotion Train the Trainer programme started in 2008 with the aim of training local health promotion and community workers to promote breast awareness through facilitated talks and workshops.

The programme aims to increase breast awareness knowledge and understanding, promote early presentation of breast cancer symptoms to GPs, and encourage uptake and attendance to breast cancer screening services among all women. However, the programme specifically targets groups of the population who are known to be at greater risk of developing breast cancer (women over 50 years), and those who are known to present late and/or have lower uptake of screening (for example, women from black, Asian and ethnic minority backgrounds and women living in socially disadvantaged areas).

This programme meets one of the key areas of impact of Breast Cancer Care’s Vision 2020 strategy document: promoting early detection and breast awareness to contribute to the optimum success of treatment.

1.2 Why a Learning Disabilities pilot?

We know that uptake of breast cancer screening is lower among women with learning disabilities than in the general population (Department of Health White Paper, 2001). Identified barriers to attending breast cancer screening among women with learning disabilities include: 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) of healthcare professionals.

NHS guidance recommends that all women with learning disabilities be encouraged to be breast aware by getting to know their own bodies so they can notice any changes while bathing and drying and by feeling and looking in a mirror (NHS Cancer Screening Programmes, 2006). There have been a number of initiatives aimed at encouraging breast awareness among women with learning disabilities, these include:

- a learning disabilities training pack produced by Breast Test Wales to be used by healthcare professionals to help women with learning disabilities make informed decisions about screening (Breast Test Wales, 2010)
- packs of laminated leaflets with a DVD explaining breast screening for women with learning disabilities created by the Leeds Partnership NHS Foundation Trust (Davis, 2008)

---

Going for a mammogram DVD³, developed by NHS Fife in partnership with Fife Council Event & Media Solutions, Supported Living Services and South East Scotland Breast Screening Centre

Keep yourself healthy: a guide to examining your breasts by Health Scotland aimed at women with learning disabilities (NHS Scotland, March 2010)

‘Your breasts, your health: supporting people with learning disabilities to take care of their breasts’ resource pack, Breast Cancer Care (2005, updated 2008)

In 2005, Breast Cancer Care collaborated with Cardiff People First and the Cardiff Parents Federation to develop user-led breast awareness information resources for people with learning disabilities and their carers/supporters. This formed part of the Extending Reach project which recommended that the Train the Trainer programme disseminate these resources when delivering training and/or breast awareness workshops to people with learning disabilities, and to specifically target carers/supporters as a key group supporting women with learning disabilities on a continuing basis. The rationale for this being that if someone with learning disabilities is unable to be breast aware for themselves, the supporter should endeavour to look out for changes in breast appearance when helping that person to wash and dress (Breast Cancer Care, 2010).

At the same time Breast Cancer Care was developing its breast health promotion services, with the formation of the Train the Trainer programme in 2008. It is within this context that a specialist Train the Trainer course specifically targeting carers and supporters of people with learning disabilities was developed. The Train the Trainer: Learning Disabilities course was piloted in partnership with Birmingham Community Healthcare NHS Trust, aimed at people who support women with mild to moderate learning disabilities and professionals facilitating health education to this client group.

1.3 The Train the Trainer: Learning Disabilities course pilot – aims and objectives

Aims: To provide trainees with the skills, knowledge and confidence to discuss and deliver breast awareness messages in an appropriate way to women with mild to moderate learning disabilities.

Specific objectives include:

- to enable trainees to understand the range of barriers (and related issues) to breast health awareness faced by women with mild to moderate learning disabilities
- to enable trainees to deliver breast health messages tailored to the level of disability they encounter in women they are working with
- to enable trainees to access a range of information, support and resources offered by organisations who work directly with this client group
- to share ideas and best practice in breast awareness with healthcare professionals and carers working with this client group.

To inform the structure and content of the pilot course a series of regional stakeholder groups were set up and consulted to ensure that the content would ultimately respond to the needs and experiences of women with learning disabilities. Organisations consulted were:

- Cardiff People First
- Mencap Cymru
- Breast Test Wales

³ www.nhsfife.scot.nhs.uk/mammogramdvd.html
2 The evaluation

2.1 Aims

This small scale evaluation was undertaken by the Research and Evaluation team following a request by the Breast Health Promotion team. The team wished to learn from the pilot, investigate potential areas for development and improvement, and try and ascertain the effectiveness and short-term impact of such a targeted training course. As such, the evaluation was both formative and summative.

The evaluation aimed to address (not exclusively) the following research questions:

- was the pilot effective in enabling trainees to confidently deliver breast awareness messages to the individuals they are working with?
- where these messages were used, how were they delivered?
- were any resources used? How were they used? How useful were they?
- was the content of the course appropriate, useful and effective in meeting its objectives?

2.2 Methods

A mixed method approach, combining a repeated measure design and semi-structured interviews was adopted for this evaluation. It included the following elements:

- a shortened version of the Breast Cancer Awareness Measure (Breast-CAM) tool[^4] to assess knowledge of breast cancer signs, symptoms and risks, confidence to deliver breast cancer awareness messages, as well as confidence in addressing the barriers to breast health. The questionnaire was administered before the course and four weeks after the course.
- a qualitative interview with trainees four to six weeks post training to find out: their views and experiences of the training; how well they felt equipped to deliver the messages to the women they are supporting or caring for; and whether the training made a difference in the way they are supporting people with learning disabilities they work with.
- an analysis of immediate evaluation forms to find out how well the training was received and trainees’ immediate thoughts around the delivery, content and resources.
- an observation of the training day and feedback from trainers around the planning and delivery process, its challenges and successes, as well as the resources involved.

2.3 Sample

[^4]: The Breast Cancer Awareness Measure (Breast-CAM) is a validated tool developed by Cancer Research UK, King’s College London and University College London in 2009 and validated with the support of Breast Cancer Care and Breakthrough Breast Cancer.
The sample included all six trainees who took part to the pilot training day. Informed consent was obtained from trainees when they registered for the course, with the option to opt out from the evaluation. The table shows the number of participants engaged throughout the evaluation process:

<table>
<thead>
<tr>
<th>No. of trainees</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>6 (100%)</td>
<td>Pre-questionnaire</td>
</tr>
<tr>
<td>6 (100%)</td>
<td>Immediate feedback</td>
</tr>
<tr>
<td>4 (67%)</td>
<td>Post-questionnaire</td>
</tr>
<tr>
<td>5 (83%)</td>
<td>Qualitative interviews</td>
</tr>
</tbody>
</table>

2.4 Outline of report

This report is divided into two main sections:

1) the pilot – planning, delivery and feedback
2) outcomes of the pilot – Breast-CAM and qualitative interviews.

Findings are presented within each of the main sections, with a final section discussing the overall findings and presenting recommendations for the future.

3 The pilot – planning, delivery and feedback

3.1 Trainees’ characteristics

The pilot training day was delivered in November 2010 and was attended by six people. All participants were female, and in paid employment within Primary Care Trusts (PCTs). Three of the participants were community learning disabilities nurses, two were health facilitators and one was a community support worker. All had some degree of regular contact with adults with mild to moderate learning disabilities.

3.2 Trainees’ expectations

Attractive elements of the course included the opportunity to gain up-to-date information and to learn how to deliver breast health promotion sessions and demystify the hospital setting to their client group. Reasons stated by prospective trainees for attending the course were:

- to be able to deliver women’s health promotion and health education sessions
- to acquire up-to-date information on best practice
- to increase understanding of breast awareness
- to empower people with learning disabilities to take control of their health.

3.3 The training day

The whole day was co-delivered by Breast Cancer Care’s Breast Health Promotion Manager and the NHS Birmingham Learning Disability Manager over a full day, covering various elements designed to address the objectives and outcomes of the course. Each module was accompanied by interactive activities and group work designed to facilitate practical applications of breast awareness messages, knowledge and skills:

- facts about breast cancer and the anatomy of the breast (quiz and breast diagram)
attitudes towards the breast (breast collage\(^5\))
- breast awareness and breast self examination (general discussion)
- what is normal? (‘Charlie’ the body silhouette\(^6\))
- choosing the right bra (general discussion)
- signs and symptoms of breast cancer (flashcards and group discussion)
- barriers to breast awareness (group discussion)
- risk factors (group discussion)
- the breast screening process (video and general discussion)
- Legalities and Mental Capacity Act /Adults with Incapacity (Scotland) Act (general discussion).

In addition to this trainers were provided with a learning disabilities pack containing:

- a learning disabilities toolkit in the form of a DVD including statistics and facts, pictures and a copy of the body silhouette to print
- Breast Cancer Care’s ‘Your breasts, your health: supporting people with learning disabilities to take care of their breasts’ resource pack, which includes a breast awareness booklet targeted at carers and frontline staff working with people with learning disabilities.

The observation of the course (made by the evaluator and a member of the Breast Health Promotion team) indicated a number of key areas to address in relation to the content and resources provided.

Firstly, observers felt that there was an overall need to emphasise why breast health promotion was different for groups with learning disabilities. It was felt that lay audiences might not have been as knowledgeable or as assertive in relation to the communication barriers involved.

Statistics were also a key feature of interest to the trainees, who requested further information about the sources of these statistics and what they meant for their client group. In particular, trainers were specifically prompted for:

- short background information on learning disabilities and screening uptake
- estimated number of deaths per year of women with learning disabilities affected by breast cancer
- proportion of men generally affected by breast cancer (unrelated or related to groups with learning disabilities).

As shown earlier, the pilot course was intended to cover a vast amount of topics within a relatively short time period. Therefore, the course would have benefited from some reiteration of key breast health promotion measures throughout – possibly after each module. In the future this may help to improve participants’ understanding of how to approach messaging around breast health promotion in the context of their own experiences of delivering support to groups with learning disabilities.

The nature of the course meant that it was highly interactive and participants were allocated more time than average to discuss any themes or thoughts triggered by the content of the course. The following themes were mentioned by participants and, as a result, may need to be incorporated in future training events either as part of the core content or the toolkit:

- learning disabilities and self image – the notion of ‘asexuality’ among family and carers contributing barriers to breast health

\(^5\) Participants were asked to create a collage of what the breast meant to them, either on a professional or personal level.

\(^6\) Charlie is a full-size silhouette on which participants were asked to stick different body parts and accessories to reflect what can be normal for themselves or their client group.
ways of tailoring the ‘look and feel’ message to people with learning disabilities, and methods and approaches to use. For example, adapted terminology of breast, creative materials, drawings and so on.
exploring meanings, experiences and issues of message tailoring from a learning disabilities perspective using case studies and individual accounts.

The last part of the day examined the legal implications of the Mental Capacity Act/Adults with Incapacity (Scotland) Act in supporting groups with learning disabilities. The aim of this module was to discuss the issue of choice, consent and health outcomes for people with learning disabilities. Trainers attempted to facilitate a discussion around the legislation in the context of the cancer screening guidelines, and the White Paper 2001. Observers felt that not all of the participants were fully engaged with the discussion, hindered by the fact that it was naturally overtaken by people who had a certain degree of familiarity with the subject.

A more direct approach to explaining the Mental Capacity Act/Adults with Incapacity (Scotland) Act, followed by a discussion around case studies, scenarios or any practice experience from trainees might be more productive. This may also be incorporated in the toolkit as part of the background knowledge and context to supporting women with learning disabilities.

3.4 Trainees’ feedback

Overall, the training was positively received by participants:
- all participants rated the quality of the training received as good or very good
- five participants out of six felt that sufficient time was allocated for the training. One felt that the training should have been allocated an extra day
- all felt that they had enough space to ask questions and share ideas
- all rated content, resources and presentations as good or very good.

When prompted for comments, participants were usually very positive on the delivery, content and format of the course. Opportunities for networking and discussion were particularly appreciated:

‘All of them were very good. Breast screening quiz was useful and enlightening.’

‘Looking always to make actual breast awareness more appropriate for service group.’

‘Discussing best practice, exploring ways to deliver breast awareness message, e.g. effective ways of communicating.’

‘Very informative. Instructors were extremely knowledgeable and delivered information at a good pace. Made for comfortable learning.’

In addition to the observation which suggests a number of improvements, trainees were able to provide their views on which sessions were the least or the most useful, and whether they had any further comments immediately after the training and as part of the follow-up interviews. The following improvements were suggested:

- more information and discussion on the physiology of the breast and its life changes
- more discussion and scenarios illustrating the applications of the Mental Capacity Act/Adults with Incapacity (Scotland) Act

---

• include areas of good practice examples and case studies showing first-hand experiences from a service user point of view
• extend the training over two days.

3.5 Toolkits and resource packs

The Learning disabilities breast health promotion toolkit

The toolkit had been used by three out of five participants in the context of their service delivery. Three out of the five also had the opportunity to deliver breast health messages in one-to-one or group settings in the intervening period between the course and follow-up interviews. One participant cascaded the Train the Trainer course to her colleagues.

Participants said the toolkit was a key resource in preparing their health promotion work and also as a potential refresher for those who had not been able to deliver any breast health promotion work yet. Consequently, trainees felt that the resource could be substantiated with further information and signposting to useful links, including Breast Cancer Care’s various, relevant webpages. They felt that this was particularly important as it would help them keep consistency in the messages and content of additional resources used.

Breast Cancer Care’s ‘Your breasts, your health: supporting people with learning disabilities to take care of their breasts’ resource pack

The resource pack had been used by two participants, both health facilitators, during their contact with carers. Both commented on how useful the resource pack was as a resource that was appropriately targeted at both carers and people with learning disabilities.

‘It was really good to give [the resource pack] to the carers, as they have something to go through with [the person they are caring for] then.’

The images included in the resource pack were particularly praised by both health facilitators. They welcomed the fact that messages could be reinforced by pictures easily accessible to carers and to people with learning disabilities as and when needed.

3.6 Planning, delivery and feedback: lessons and recommendations

Lessons learnt

Feedback and interviews with trainers revealed a very positive experience of this pilot project.

Some of main outcomes for both staff teams and organisations were in terms of knowledge exchange and transfer of expertise. Breast awareness workshops were delivered to the Learning Disability Services Team at the Birmingham Community Healthcare NHS Trust and a one-day introduction to working with people with learning disabilities was delivered to the Breast Health Promotion team at Breast Cancer Care. It was felt that this partnership provided an exemplary model of developing support services using expertise from the NHS and the Voluntary Sector.

As revealed in the feedback, the trainers felt the day had been successful. There was an acknowledgement that this group of trainees had provided a useful training ground for the pilot, and that the overall development of the course should be informed by the discussions that had
occurred during the day. As a result of these discussions, it was recognised that existing breast health promotion trainers would need further training into interpreting the Mental Capacity Act/Adults with Incapacity (Scotland) Act in order to feel competent to discuss its impact on decision-making for women with learning disabilities and their carers.

In addition, trainers acknowledged that a two-day course may have been preferable for this pilot and that the course would need to be tailored to reflect various levels of knowledge and different audiences (for example, carers, community workers and nurses). However, it was felt that a one-day option would be more popular with healthcare professionals and carers to meet their time constraints.

Challenges

Limited resources and time were key challenges, especially as the set-up time (from the conception to the delivery) only took a few weeks. The project was largely successful due to the dedication, personal and professional time invested and only made possible with the formal agreement of management teams from both organisations. Costs were kept to a minimum and limited to room hire, lunch and producing the materials and toolkit.

Despite an implicit expectation that each organisation proactively promote the course, the marketing plan was not formalised and the amount of time needed for this was underestimated between the two organisations, leading to misunderstanding. As a contingency plan, the promotion was restricted to individual networks primarily within the NHS sector. On a positive note, the snowballing effect generated new contacts and raised interest for further courses.

Recommendations

The following recommendations have been informed from observation notes, trainees’ feedback (forms and interviews) as well as trainers’ reflections:

- consider refining the aims and objectives of the course to make it more relevant to the experiences of women and men with learning disabilities and state the specificity of this course within Breast Cancer Care’s Breast Health Promotion service

- consider giving more emphasis to the 5-point code and, specifically, how to tailor this message and communicate effectively with people with learning disabilities

- consider creating a quick bullet point guide summarising how to tailor the ‘look and feel’ message to women with learning disabilities. The pilot course suggested that the following key points may be useful:
  - fit breast health activities into existing routine (for example, personal healthcare plans) and regularly review
  - carers are key contacts – how comfortable are they with intimacy issues and how do they feel about breast health?
  - be direct and specific to avoid confusion; recommend ways of looking and feeling, how and when
  - be creative and pragmatic in approach/methods used.

- consider taking a didactic and plain English approach to explaining the Mental Capacity Act/Adults with Incapacity (Scotland) Act. Case studies may be included to illustrate
potential implications of the legislation around health choices, consent and outcomes for people with learning disabilities

- consider integrating the experiences of breast screening from the point of view of a woman with learning disabilities to address the specific issues raised in the course

- consider maximising the use of the toolkit as both a resource and a long-term reference for trainees. Perhaps include more background information about the Mental Capacity Act/Adults with Incapacity (Scotland) Act and its implications, as well as further statistics about breast cancer and learning disabilities and a quick guide to adapting breast health messages to a learning disabilities context.

4 Outcomes and impact

4.1 Levels of breast awareness

Knowledge of breast cancer signs and symptoms

Levels of recognition were increased after four weeks of attending the course, with an average increase of 21%. The majority of participants were able to recognise most of the signs and symptoms of breast cancer (more than 75%), with the exception of redness of the breast skin.

Fig.1: Knowledge of breast cancer signs and symptoms

Levels of recognition were positive (more than 80%) for most of the classic symptoms such as lumps and physical manifestations (for example, bleeding, discharge, puckering and changes in shape).

At the other end of the spectrum, nipple rash and position as well as redness of skin were not signs that the participants easily recognised as possible symptoms of breast cancer before the course. However, they were more aware of these symptoms after attending the course.
The mean number of recognised signs and symptoms was seven signs out of 11 before the course and 10 signs out of 11 four weeks after the course – meaning that participants recognised more signs and symptoms after the course than before.

**Knowledge of age-related and lifetime breast cancer risks**

Knowledge of lifetime risk among participants was good, with four out of six participants (67%) recognising that 1 in $9^8$ women were at risk of being diagnosed of breast cancer before the training, and three out of four (75%) recognising this after the training. None of the participants ticked any of the other options given (one in 100 and one in 1000 women) either before or after attending the training.

![Fig. 2: Knowledge of lifetime risk](chart)

When asked about age-related risk, none of the participants answered the correct option (a 70-year-old woman). Options given to this question included a woman of any age, a 70-year-old woman, a 50-year-old woman and a 30-year-old woman.

Also, despite the course promoting the message that anyone is at risk of breast cancer, only one participant selected this option after attending the course (25%). A 50-year-old woman was the most common answer selected by participants with three out of six selecting this before the training (50%), and three out of four at the follow-up stage (75%). This result may have been due to confusion over the age at which a woman receives her first letter of invitation for the breast screening programme.

---

8 At the time of Breast-CAM administration, the new statistics from Cancer Research UK on lifetime risk (1 in 8) were not yet published.
Knowledge of NHS Breast Screening Programme

Before the course, despite most participants feeling confident about their capacity to address barriers to attending the NHS Breast Screening Programme, their responses demonstrated mixed awareness levels of the programme. The course had a positive effect on knowledge level, but seemed to have an adverse effect on the participants’ confidence to address barriers to attending the NHS Breast Screening Programme – from five participants out of six (83%) before the course to two participants out of four (50%) one month after the course.

The level of knowledge about the age at which the first invitation letter was sent remained high (more than 83%), while the knowledge about the age of the last invitation increased dramatically, from none of the participants to all of them (100%) identifying the correct age. In contrast, the confidence to address barriers to attending the NHS Breast Screening Programme decreased.
Breast awareness behaviour

The occurrence of checks remained relatively similar in the interim period, at a frequency of once a month. When comparing the data on an individual basis for the four respondents who answered the questionnaire before and after the training, their behaviour remained exactly the same at both stages.

However, when asked about their confidence to detect a breast change, two out of the participants (50%) rated their confidence higher after attending the training.

Fig 5: Confidence in detecting breast change

Confidence to deliver breast cancer awareness messages

The data shows that after attending the training participants felt more confident telling women about their risk of developing breast cancer, explaining the difference between breast awareness and self-examination and describing how the NHS Breast Screening Programme works. All participants reported higher levels of confidence in these areas (more than 40%).

---

9 Lickert scales were coded as follows: 1 – at least once a week, 2 – at least once a month, 3 – at least once every six months, 4 – rarely or never.
Conversely, a few areas were reported to have registered negative outcomes. In particular, participants felt less confident in their ability to encourage women to visit their GP (-33%). Discussing the advantages of early treatment and dealing with language barriers were two other areas where the course did not have any impact.

**Confidence to address the barriers to breast health**

Four participants out of six (83%) reported feeling ‘slightly confident’ addressing the main barriers to breast health and wellbeing before attending the training.

The graph below shows the mean score for barriers to: being breast aware, going to see the GP and accessing the NHS Screening Programme. While participants reported immediate increased confidence in addressing barriers to breast health, the intervening period between the end of the course and the follow-up revealed a slight decrease in confidence for the group in two of the three areas. Possible explanations include some participants not being able to apply their skills, and therefore feeling unsure about how to apply their newly gained skills and knowledge, and other participants facing various challenges when delivering breast awareness messages, and therefore feeling less confident in the early days.
4.2 The trainees’ journey: the process

Themes arising from participants’ interviews uncovered similar experiences of attending the course and showed the impact of the course not only for themselves personally and professionally but also for their client group. All the participants interviewed – whether or not they were able to deliver courses in the intervening period – described similar stories of change. Figure 8 below summarises one trainee’s story of change, describing the different outcome levels.

Self awareness

All the participants found that the course was thought-provoking and challenged them on their own level of breast awareness. The course had helped clarify facts and figures as well as giving them tips on how to talk about breasts. For example, participants who considered that they had a good level of awareness prior to the course having indirectly experienced the impact of breast cancer themselves, acknowledged that it had changed their own awareness to a more grounded standpoint.

‘It is alright having a little bit of knowledge because you have known people who’ve gone through [breast cancer], but to sit down and go through it all with somebody... is something different.’
‘It made me realise that you need to be breast aware no matter what age you are.’

The extent to which participants felt they increased their level of awareness varied according to their prior knowledge. One participant who attended both the general and Learning Disabilities Train the Trainer courses reported that attending the latter had reinforced and refined her understanding of breast awareness and made her aware of the areas she needed to improve on. For the other participants, the course had resonated with them as women first on a personal level by making sense of the information, and then as professionals trying to think about how to apply this new information.

Breast self-examination v breast awareness

Breast awareness was a new concept for most of the participants interviewed (except one). Working within clinical settings, they were more familiar with the term ‘breast self-examination’. Some of the challenges faced by several participants related to breast awareness messages for women with learning disabilities and their carers, which at first they felt were not defined and did not have boundaries. The course demystified the concept of breast awareness by demonstrating and testing (through activities) how breast awareness could be relevant to people with learning disabilities.

Participants reported that the course had led them to review their own practice, and particularly how they facilitated and communicated general wellbeing and breast health promotion messages to their client group. For example, the training emphasised the ‘look and feel’ message rather than the ‘hunt the lump’ directive:

‘I was of the opinion that we were still getting people to look for breast lumps and things like that. It has obviously moved on... and that is something I have taken away from [the course]. A more general looking at your breasts rather than focusing on lumps and bumps... which I think is better for people with learning disabilities because if you get them to look for a lump, they will just focus on the lump on not anything else.’

Confidence and competency to deliver breast awareness messages

The course promoted a practical approach and invited participants to test out different ways in which they could present the breast awareness messages to participants. As described earlier, various materials were introduced to them and used during workshop sessions.

Out of the four participants interviewed, three had delivered breast health messages. The table below summarises the types of audience reached and the settings in which the messages were delivered.

<table>
<thead>
<tr>
<th>Audiences reached by trainees and settings</th>
<th>Group setting</th>
<th>One-to-one setting</th>
</tr>
</thead>
<tbody>
<tr>
<td>Professionals</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>Carers</td>
<td></td>
<td>✓</td>
</tr>
<tr>
<td>Women with learning disabilities</td>
<td>✓</td>
<td>✓</td>
</tr>
</tbody>
</table>
Clearly, the course motivated participants to go and facilitate sessions themselves as they felt well equipped to do so. Most of the participants interviewed felt that the course had been successful in demonstrating how to address the subject. This had increased their confidence in tackling the issue when, prior to the course, they would have perhaps been less forthcoming.

‘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.’

The most notable impact on participants was in the way their general wellbeing health promotion practice was altered towards a more practical and inclusive approach. In particular one of the participants explained how she felt that the course positively affected her competency to take a different approach which was more adapted to people with learning disabilities.

‘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].’

Another participant felt that the course gave her the confidence to tackle the issue with reticent carers and parents. She felt that the information and knowledge that she gained enabled her to challenge carers’ and parents’ perceptions of breast cancer and learning disabilities.

‘Some people’s parents or carers might not tolerate how we teach them to be breast aware and it is brushed under the carpet... but by gaining the knowledge and the background information you can say to the carers why it is so important and there are ways of making the information easier for someone with a learning disability.’

Impact on client group

Activities described by the trainees provided case stories on the type of impact that the course could have on the end user. While not being exhaustive, these case studies demonstrate clear, tangible behavioural changes brought about by the Train the Trainer cascading model.

- Case Story 1: Impact on carers

Participant A (Health Facilitator) has used the learning disabilities packs to raise awareness of breast health with carers and to demonstrate the benefit of breast awareness to both themselves and the person they are caring for. The packs were sent through as a mass mailing to targeted homes along with a letter highlighting the need to act on NHS Breast 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.

- Case Story 2: Impact on women with learning disabilities

Participant A (Health Facilitator) used health action plans to deliver the breast awareness message 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 unusual changes were observed. Following this, the young woman started to check herself at home and found a lump. She went to the doctor straightaway to get it checked.
Participant D (Health Facilitator) delivered two group sessions in a women’s wellbeing centre for people with mental health problems. Instead of using a silicone breast to show how to look for lumps she used it to demonstrate the need for correct bra fitting to improve your breast health outcomes. The message impressed as much onto participants as it did onto the centre workers who took all the women to Marks & Spencer for a bra fitting. Afterwards all women were given two fitted bras. Participant D was asked to facilitate regular sessions throughout the year.

- **Case Story 3: Impact on professionals**

Participant C (Community Learning Disabilities Nurse) cascaded the training onto her colleague, and introduced the learning disabilities packs as well as the materials that were used during the course. They are now planning to deliver further sessions in their area targeting specialist community nurses and newly appointed health facilitators in the breast screening unit where she works.

**5 Summary**

This pilot successfully met its objectives by equipping trainees with the relevant knowledge to deliver breast health promotion to women with learning disabilities and their carers. In addition, the transfer of expertise from general health promotion to health promotion targeted at people with learning disabilities added value to this project. Both Breast Cancer Care and the Birmingham Community Healthcare NHS Trust Learning Disability Services team reported that this model of partnership had achieved tremendous results for their respective staff members and organisations in terms of capacity building and development.

There is a clear process of service improvement outcomes spearheaded by participants’ attendance to the Train the Trainer: Learning disabilities course. The impact of the training not only affected learners’ knowledge but also went on to transform their own perceptions and attitudes towards breast health. Trainees acknowledged how their practice shifted as a result of the realisation that the breast self-examination messages were too prescriptive for people with learning disabilities and less likely to be empowering.

For participants who had the opportunity to practice, test and challenge their newly acquired knowledge and skills in the interim period between the course and the semi-structured interviews, the outcomes were definitely stronger and levels of confidence increased or were maintained. The shift from a ‘hunt the lump’ message to breast awareness was one of the biggest acknowledged gains by the participants. They felt this was a more flexible approach to breast health promotion and that they were better equipped as a result.

The creative and practical nature of the course encouraged trainees to take a more hands-on and inclusive approach with this client group and their carers, by using materials and tools, facilitating discussions about what it means to be breast aware, and how to do this. As some of the trainees felt more able and confident to deliver breast awareness messages, outcomes went past the transmission of knowledge. The emphasis on the clarity of the message meant that trainees were favouring direct approaches, thus generating direct and meaningful results – as shown in the reported case stories.

One of the key areas for improvement is the content of the course, which needs to be more specific to the experiences of women with learning disabilities. In particular, there was clear evidence that the structure of the course would benefit from more discussion about how to
encourage women with learning disabilities to access their GP. Another area was the provision of continuing support to trainees in addressing specific barriers to being breast aware via online updates, case studies or a refresher training (for example, using e-learning facilities) in order to increase their self-confidence in the short and long term.

Finally, this pilot evaluation suggests that, provided the right group of professionals and healthcare and social care providers are targeted, the potential impact on the public could be large scale and early presentation outcomes for this particular group could be improved. For instance, there were clear indications that the course should target professionals who are proactively engaging with the learning disabilities’ wellbeing agenda and whose remit is to increase health outcomes for this client group.

6 Recommendations

The course

6.1 Refine the objectives and content of the course to address both the needs of lay and specialist audiences and make it directly relevant to the experiences of women with learning disabilities.

6.2 Clarify age-specific messages related to risk factors and the NHS Breast Screening Programme.

6.3 Include interactive content that looks at ways to encourage women to access their GP and tailor messages on being breast aware – for example, consider creating a quick bullet point guide summarising how to tailor the ‘look and feel’ message to women with mild to moderate learning disabilities, and the use of role play in workshops.

6.4 Consider extending the length of the course to two days to implement recommended suggestions – thus strengthening the outcomes and impact of the course.

Support to trainees

6.5 Consider providing refresher courses or ways to keep trainees up to date. A forum is already provided to all learners, however a more interactive approach (for example, e-learning facilities) to keep up to date and in touch with Breast Cancer Care might be better received as it will provide flexibility of access and value for money. Lessons in engaging with trainees in the long term could be learned from the existing healthcare professional engagement model – especially as it is directly relevant to the strategic aspirations of Breast Cancer Care’s Vision 2020.

6.6 Review the content of the toolkit and supplement this with additional information so that learners can use it as a long term reference.

6.7. Consider separating the toolkit into two main sections so that trainees can pick and mix various elements:

- lay/starter level information with key documents and references (for example, implications of the Mental Capacity Act/Adults with Incapacity (Scotland) Act, key guidelines, facts and figures, case stories, and so on)
- specialist/advanced level information (for example, further legislations, notions of asexuality and self image, and so on) might be provided as additional reading.
Marketing

6.8 Adopt a targeted marketing approach to professionals whose remit it is to deliver the wellbeing agenda in the community. The data showed a clear distinction between health facilitators who had a proactive approach to reaching carers and groups with learning disabilities, and community nurses (specialist or otherwise) who were only acting upon referrals from general practitioners.

6.9 It is advised that an abridged version of the Train the Trainer: Learning Disabilities course is actively marketed to trainees who have attended the general Train the Trainer course. Ensuring that they receive this bolt-on training may decrease chances of them feeling less confident in these specific, but relatively rare, circumstances.

Sustainability

6.6 Accreditation may be a potential avenue for the course. This process lends itself to a multi-level approach to the Train the Trainer portfolio, with the Learning Disabilities course supplementing the general version and expanding Breast Cancer Care’s existing expertise.

6.7 Further research into the impact of the rolled-out Train the Trainer: Learning Disabilities course on to trainers and the community will need to be undertaken in order to ascertain the long term benefits of breast health promotion as a preventative intervention among people with mild to moderate learning disabilities.