

## The role of community nurses and residential staff in supporting women with intellectual disability to access breast screening services

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### Abstract

**Background** Women with intellectual disability (ID) are surviving to the age group at greatest risk of developing breast cancer (50–69 years). These women are more likely to experience a greater number of risk factors placing them at an advanced threat of developing breast cancer. However, as a result of cognitive deficits and communication difficulties these women are dependent upon staff to support them to attend the breast screening clinics.

**Aim** The aim of this paper was to examine how community nurses and residential staff support women with ID to access breast screening services.

**Methodology** Six focus groups were held with community nurses and residential staff who work in the field of ID in one region of the UK. The focus groups were tape recorded and the transcriptions were subjected to a thematic content analysis.

**Findings** Although many of the participants recognised the risk factors and signs/symptoms of breast cancer, there was still a deficit of knowledge. Both positive and negative experiences of women with ID attending for breast screening were reported;

however, greater discussion focused on the latter.

The participants identified 'a lack of health educational material' and also negative 'emotions, attitudes and physical barriers' as inhibiting factors for attendance.

**Discussion** This paper highlights the need for developing a health promotion programme for women with ID focusing on breast awareness and information on screening, and also healthier lifestyles. Breast awareness via visual checks was identified for women with ID who refused to attend the breast clinics; however, issues of informed 'consent' and 'vulnerability' were raised for staff and also family carers having to undertake these checks. Development of user-friendly health educational literature using 'pictures, symbols, signs' and simplified words should be accessible to all ID staff, healthcare staff, and also women with ID.

**Keywords** accessing, breast cancer, breast screening, intellectual disability, women

### Background

People with intellectual disability (ID) are living longer and therefore will experience the same age-related illnesses as people in the non-ID population, including cancer (Patja *et al.* 2001; Tuffrey-Wijne

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*et al.* 2007). Bittles *et al.* (2002) reported that the average life span of women with an ID to be 71 years of age, which indicates that in developed countries, most women with an ID will survive to the age group at greatest risk of breast cancer (50–69 years). It is estimated that the prevalence rates of breast cancer in women with ID are similar with non-disabled women but estimates may increase as this population continues to grow older (O'Regan & Drummond 2008).

However, there is growing evidence to suggest that women with ID are more likely to experience a greater number of risk factors for breast cancer, placing them at an advanced threat of developing cancer (Willis *et al.*, 2008). These include leading a more sedentary lifestyle (McGuire *et al.* 2007), low levels of exercise (Messent *et al.* 1998; Draheim *et al.* 2002; Temple & Walkley 2003) and consuming high fat diets (Ewing *et al.* 2004), all of which can contribute towards obesity which is an added risk for breast cancer (Magnusson *et al.*, 1998). Another risk factor is nulliparity, not giving birth, which can result in a fourfold increase in risk of developing breast cancer in women without ID (Judkins & Atkins, 2001); although this has not been explored in women with ID. Furthermore, women who experience early menarche (first menstrual cycle) and late menopause (absence of menstrual cycle after 40 years of age) are thought to have an increased risk of developing breast cancer (McPherson *et al.* 2006). However, information on the early history of menarche is less often available for women with ID (McCarron & Pekala Service 2002). More worryingly, research as shown that earlier menopause (before 40 years of age) is also more likely to be experienced in women with ID than women in the general population (Seltzer *et al.* 2001; Schupf *et al.* 1997, 2003).

Breast cancer incidence and mortality are also influenced by the availability of health education, health promotion activities and breast cancer screening services (Blanks *et al.* 2000). Even when these services are available, accessibility and utilisation of screening has been identified as a major issue for marginalised population subgroups such as those with low levels of literacy, non-English speakers, women with physical disabilities and women with ID (Ridley, 2000, Sullivan *et al.* 2003). The Disability Rights Commission (DRC 2006) analy-

sed data from general practitioner (GP) practices on uptake of breast screening in Wales for women with ID: 26% of women with ID attended for breast screening compared with 71% of women without ID.

Many women with ID fail to attend breast screening on invitation. Likewise they do not use breast screening services which consequently leads to a delayed diagnosis with the result that breast cancer is not detected until the latter stages where treatment may be ineffective (Davies & Duff 2001; Sullivan *et al.* 2003; DRC 2006; Gibson 2006). Many difficulties arise for the women with ID regarding the letters of invitation for attendance at the breast screening clinic, assuming that all women with ID receive the request as many women may not be registered with a GP (Biswas *et al.* 2005). Communication limitations and cognitive deficits make reading the letter complex, if not impossible, thereby placing greater emphasis upon family carers and residential staff to read the letter on their behalf (Pehl 1999; Alborz *et al.* 2003). These carers then must decide whether to support these women with the ID to attend for the screening, deciding if it is necessary or not (Smith 2003; Reynolds *et al.*, 2008).

As a result these carers play a significant role in supporting the women with ID to manage their health care needs and aiding them to access appropriate health care expertise. However, many carers may not have the detailed medical knowledge required to identify the risk factors and signs/symptoms of breast cancer. It has been found that many GPs and primary healthcare staff have little, if any, knowledge and training about working with women with ID (Stein 2000; Phillips *et al.*, 2004). This places women with ID in a vulnerable position, unable in most part, to access health care for themselves but also with reduced access to those with expertise in health matters of people with ID.

In addition to care provided by family members or residential staff, community nurses working with women who have ID are also likely to be involved in their physical care. Therefore, these community ID nurses (CIDN) are in an influential position to identify and detect any signs/symptoms of breast cancer, by directly educating/training both family carers and residential staff to recognise and report any changes/abnormalities. It can be argued that

CIDN and residential staff are in a position that could influence and reverse the trend of cancer-related deaths in people with ID (Willis *et al.*, 2008).

Moreover, CIDN and residential staff have the potential to become more involved in health education, health promotion activities, early screening and education of these women as well as their family carers, thus making more appropriate referrals to the GP and breast screening clinics. This information will also enable health promotion agencies, GPs and practice nurses, breast screening nurses as well as a wide range of ID staff; to be more proactive in identifying the early signs/symptoms of breast cancer before the cancer becomes more advanced, thereby preventing unnecessary and early death (DRC 2006; Mencap 2004, 2007; Health Care Commission 2007; Department of Health 2008; Joint Committee on Human Rights 2008).

The aim of this paper was to examine how CIDN and residential staff support women with ID to access breast screening services.

## Methodology

A focus group methodology was used to extract the depth of personal experience from front-line care staff on how women with ID accessed breast screening services.

## Participants

This study used a series of focus groups with CIDN and residential staff who voluntarily agreed to participate in this study. In total there were 29 participants CIDN. Three focus groups were organised with CIDN with between five to six participants in each group. Second, three focus groups were held with residential staff with between four to five participants in each group. The focus groups were held in three separate Health & Social Care Trusts (H&SCT) across Northern Ireland. The CIDN were selected through a purposeful sampling approach from the total population of all CIDN ( $n = 60$ ) working within the three HSCT. A total of 16 CIDN staff participated in the focus group interviews. Of these the majority were CIDN ( $n = 13$ ),

three were student CIDN, two were nurse managers and there was one team leader. The majority of participants were female (93.4%), over three-quarters were aged 30 years plus (81.2%) and half of the participants (50%) were in post for five years plus. Likewise, a purposeful sample of residential care staff ( $n = 13$ ) was also selected from across a range of supported housing and residential accommodation for people with ID. There were 10 residential workers (76.9%), two nurse managers (15.4%) and one student nurse (7.7%). The majority of the residential staff were female (84.6%), all were aged 30 years plus (84.6%) and less than half of the participants had been in post for 5 years plus (53.9%). The criterion for inclusion within this study was based upon the participant being a community nurse and/or a residential staff member who have supported women with ID to access breast screening services in the past 12 months. The overall response rate to the invitation to participate in the study was poor as a result of scheduling difficulties due to sick leave, work commitments and annual leave.

## Interview format

In order to guide a consistent flow to the focus group discussion a semi-structured interview guide was developed based upon topics generated through the literature (Sullivan *et al.* 2003; Gibson 2006; Baxter & Bradley 2008; O'Regan & Drummond 2008) and the research team's personal experience (see Box 1). This focus group format was structured into three sections. Section one examined the staff's own knowledge of the risk factors of breast cancer. Section two explored the staff's experiences of supporting women with ID to access breast screening services, and/or identify why women with ID refused to attend. Section three sought information regarding the barriers for not attending and the solutions to support the women to access such services.

The focus groups took place in a location convenient to the participants' place of work and which could provide a private environment. The focus groups lasted between 40 and 60 min and were audio-taped. The first focus group with the CIDN acted as the pilot study. Discussion with participants afterwards resulted in no changes to the inter-

**Box 1** Interview guide for the CIDN and residential staff

Have you or your team ever supported someone with ID who required breast screening services/breast cancer services?

**Prompts**

- Who referred?
- Reason for referral
- Diagnosis?
- Length of cancer specialist involvement?
- Which cancer professionals were involved?
- What the person's support needs were?
- How were these needs met?

If you have experience caring for women with ID who had breast cancer please select one example and describe.

What hindered the care for this person; what helped to make things successful?

What did help/or would perhaps have helped your team in supporting a woman with ID who required breast screening/cancer services?

Where would you go for support and advice when providing breast screening/cancer care to a woman with ID?

What education and training have you had in relation to breast screening, cancer health promotion/education for people with ID?

Have you ever worked in partnership with breast cancer specialist services?

view format or process and this data formed part of the final findings (Parahoo 2006).

**Procedure**

Team leaders within each of the three community ID nursing areas, and similarly managers from across a range of residential accommodation, were contacted and asked to distribute an information pack and consent form to potential participants. The information pack outlined the purpose and nature of the study and expressed their agreement to participate through the return of a consent form to the research team.

**Ethical considerations**

The Office for Research Ethics Committee in Northern Ireland granted ethical approval for this study; permission was obtained from the three H&SCTs. Consent was sought and secured in

writing from each participant. No identifiable information about the participants would be used in any reports and the respondents were informed that the tape recordings would be destroyed at the completion of the study; although the transcripts were retained for 5 years.

**Data analysis**

In order to ensure the rigour of the data collected, the transcripts were subjected to a thematic content analysis using Newell & Burnard's framework (Newell & Burnard 2006; see Box 2).

**Findings**

A process of thematic content analysis was used to analyse the focus group data and four core themes emerged; these are presented below with participants' excerpts.

**Box 2** Burnard & Newell's thematic content analysis

Stage 1: Two members of the research team were present at each focus group.

Stage 2: All focus groups were digitally recorded and transcribed verbatim.

Stage 3: Transcripts were analysed using open coding.

Stages 4 and 5: Themes and sub-themes were grouped and linked. The emergent themes and sub-themes were rechecked against the transcripts by both the first and second author independently.

Stage 6: Relevant textual quotes from the transcript were married up with the main themes and sub-themes.

**Knowledge and awareness of breast screening and breast cancer***Importance of breast screening*

Across the six focus groups there was a consensus for the women to undertake regular breast screening, with the participants highlighting the importance of early detection and the prevention of breast cancer from developing into a terminal illness. The participants also indicated that these women 'were entitled to the same services . . . . rights' (FG4) as other women without ID to access breast screening services.

*Risk factors for breast cancer*

In terms of the nurses and residential staffs' knowledge of the risk factors associated with breast cancer, the majority of participants were informed. 'Family history' and 'genetic inheritance' were clearly identified by many as a leading cause of breast cancer; and also other cancers. However, both groups of informants stated that for many of these women, and also men with ID, particularly if they had been 'resettled from long-stay hospitals into the community' (FG4), their family histories of breast cancer were not fully known.

Many of the participants reiterated accounts of women with ID that led 'sedentary lives' and 'unhealthy lifestyles', this included 'poor diet' and 'a lack of exercise' that has subsequently led many of these women to become 'obese': a cluster of lifestyle risk factors for developing breast cancer that could be prevented. This can be illustrated in the following:

I think that diet has a big impact on any form of cancer, not only breast cancer, and diet is very

poor amongst our women, I mean the five a day just doesn't hit home. (FG2)

There are a number of women with ID who would be quite set in their diet . . . . especially if they had autism and they wouldn't want to try new things so by choice; they would have a limited diet. (FG2)

A few of the participants reported how some of the women were prescribed 'hormone replacement therapy (HRT) . . . . long-term' and how this may be another risk factor in developing breast cancer: although many of the respondents did not report this. However, a number of other risk factors were not recognised by both groups of participants these included: increase risk with age, ethnicity, previous breast cancer diagnosis, early menarche, dense breast tissue and nulliparity.

*Signs/symptoms of breast cancer*

Across all the focus groups there was evidence of the participants being aware of some of the signs/symptoms (i.e. changes in breast shape/size/colour, presence of a lump, discharge, pain, rash/inflammation). However, the residential staff reported fewer signs/symptoms than the CIDN. Moreover, neither group identified swelling under the armpit and collarbone, pain in part of the armpit, additional changes in the nipple such as shape, position or rash.

**How staff support women with ID to access breast screening services**

Within this theme, two sub-themes were clearly identified.

*Health education and health promotion*

A number of the CIDN reported supporting the women to attend their GP, practice nurse and if needed the breast screening clinics. This included 'providing user-friendly literature' on how to look after your breasts, supporting the women to self-examine and report any abnormalities; although not all the CIDN were aware of this material. Many of the residential staff also indicated that they were not aware of such accessible literature. In addition, a number of the CIDN 'arranged visits to the breast screening clinic prior to the initial appointment', 'organised transport' and also 'accompanied the woman to the clinic for the mammogram'. This is illustrated by the following excerpt:

Accompanying them to the breast screening clinic, taking them up beforehand and showing them around . . . . . and getting leaflets and explaining what the procedure is. (FG3)

The participants also highlighted the emotional support they provided to the women. Many of the CIDN reported offering advice to both the woman with ID and also their family member in relation to breast examination and attending for screening:

Advising the women and their families of the importance of taking up the opportunity of the breast screening . . . . . very often families think, oh you know, because they have an ID that they don't require the same level of screening that everyone else does. It's about advising them that yes it is very important. (FG3)

Not only did CIDN offer advice to the women and families but they also provided information and support to the breast screening nurses on topics such as communication. This has helped the breast screening nurses to provide more in-depth support where possible to the women with ID 'ensuring extra time is given' and 'giving reassurance'. One CIDN stated:

I have contacted the breast screening nurses before the women with ID attends, explaining what this person's particular needs will be on a given day and making sure that the nurses are aware of her needs. (FG3)

**Factors enabling and inhibiting women with ID regarding breast screening**

The first section of this theme will focus upon factors (or sub-themes) that enabled the women to attend for breast screening.

*Invitation letter and use of friendly literature*

In terms of how women with an ID were informed about breast awareness and encouraged to attend for breast screening, the main point of access was from the invitation letter forwarded by breast screening unit: with both CIDN and residential staff supporting the women to read the letter. Where available user-friendly literature was also used to educate these women to become self-aware and to explain the process of the breast screening clinic.

*Recalling upon positive past experiences*

The participants reported that for some women attending the breast screening clinic the experience was reported to be positive, as clear information was given in an accessible format which made the procedure less frightening and uncomplicated:

She goes to the mobile down at the hospital and she handles it all very well, but again, originally she was given all the information and was reassured and educated at the time. (FG4)

The second section of this theme will examine the factors (or sub-themes) that inhibit women with ID to attend for breast screening.

*Lack of knowledge and understanding*

Some of the participants indicated that as a result of the women's poor literacy skills, limited communication skills and level of understanding, they would have limited knowledge about breast cancer and the need for regularly undertaking self-examinations and going for breast screening.

If the women with an ID were sent an invitation to attend breast screening then their literacy would act as a barrier as they may not understand the letter and put it in the bin. (FG1)

Because they have limited understanding of what to look out for and unless a member of staff

knows that there is a lump or discharge  
 . . . . . the woman isn't going to recognise that.  
 (FG8)

#### *Negative emotions, attitudes and physical barriers*

A number of negative emotions and attitudes were identified by the majority of the participants across all the focus groups in an attempt to explain why some women with ID refused the opportunity to attend for breast screening. These included: 'privacy' (i.e. fear of undressing), 'fear and anxiety' (i.e. the procedure itself and also the potential outcome if signs discovered to be genuine), 'discomfort and pain', 'practical considerations' (i.e. appointment clashes with day-time activities, physical distance of hospital from home, cost of transport, wheelchair access, car parking) and 'additional health problems' (i.e. physical disabilities, co-existing mental health conditions). Issues of staff resources within the residential focus groups were also raised:

Some women who are called for screening and they can be very disturbed, having poor mental health. It's a major ordeal going up to the hospital for some women like, so they just refuse.  
 (FG4)

Some women with autism . . . tactile defensive issues, the smell, the curtains, the buzzing and the machinery. They just can't cope with it . . . . . they can't handle touch. (FG4)

Both groups of participants also reported assisting women to attend the clinics for a mammogram; however, for some women their experiences were found to be negative. The participants reported that the overall experience was stressful in terms of 'fear', 'pain' and concerns about the 'outcome':

Fear. Very, very afraid of the unknown of what is going to happen. (FG2)

It was very distressing for the woman who is getting that letter [results of the mammogram].  
 (FG5)

We have had the other experience where women with ID haven't cooperated and they have shouted and screamed and it has been very difficult for the breast screening nurses. (FG6)

#### *Lack of health promotion and education*

The participants reported that the women, and also their family carers and/or residential staff, were only made aware of the woman's appointment for breast screening after receiving an invitation letter from the breast screening unit. Some of the participants highlighted that there was a lack of 'importance' and also a dearth of health promotion (i.e. 'advertising') and health education (i.e. 'literature') in relation to breast screening for women with ID:

It's so personal and not understood by many women. I don't know of any health educational sessions given within the day centres where breast examination has been taught. And maybe part of that is that it could be misinterpreted by the woman. (FG2)

There is a lack of education for these women as they are not told about cancer, never mind breast cancer. These topics are covered over . . . . . cervical screening is another one. Just taboo. (FG3)

#### *Lack of importance given to the need for breast examination and breast screening*

A number of the CIDN reported that for some family carers they made the decision not to inform their daughter/sibling about the breast screening appointment. Family carers 'didn't perceive the appointment as a priority', 'it was a taboo subject that they (family carers) did not want their loved ones (woman with an ID) to be aware of' or 'it wasn't regarded as appropriate for their family member'. One CIDN stated:

The older carers would also be of a generation were they missed the self-breast examination move and would not advocate the importance of breast screening. (FG1)

Two CIDN highlighted as many family carers were older than their daughter, additional issues arose pertaining to supporting both the woman with ID and also the elderly family carer along with transport:

Very often the woman with the ID needs to be assisted to attend the breast screening clinic and there is no motivation in the part of the older

family carer to bring them: so how can it happen?  
(FG2)

### Solutions to overcoming the factors that inhibit women with ID to attend for breast screening

A number of potential solutions were discussed among both groups of informants on how to overcome some of the factors that inhibit women with ID to access breast screening services and three sub-themes were identified.

#### *Development of health education material*

There was a consensus among the participants to develop a range of health education material that was 'user friendly', using 'pictures, symbols, signs' (i.e. 'Makaton', 'Widget') and simplified words. Information leaflets, booklets and videos/DVDs were highlighted as the appropriate mediums for this information that should be placed in a wide range of facilities such as residential facilities, health centres, day centres and also in the breast screening clinics.

Using a range of materials to educate women with ID including a DVD, leaflets, something women focussed using pictures, signs and symbols (Makaton) where necessary. (FG1)

#### *Development of health promotional activities*

There was some discussion among the participants about educating the women with ID to 'self-examine', which focussed upon the ability of the women and whether there were associated physical disabilities and other related health conditions. Likewise, several CIDN reported 'teaching family carers' to examine the women's breasts if they were unable to self-examine, but some participants raised issues relating to 'vulnerability' and the potential issue of 'abuse' that this may create.

It would be a challenge to educate women with ID to examine their breasts and attend breast screening after so much time and effort has been devoted to getting people with ID to protect their bodies. (FG1)

We had a client who had asked us to check her breasts and we had explained that it was inappropriate for us and really we couldn't. . . . So we asked our area manager if she would do it

because she was a nurse and again it was explained no . . . (FG5)

Staff need protecting as well . . . there is a lot of issues in relation to staff, you know, accusations that can be made against staff. (FG5)

Some participants highlighted the need for having educational sessions developed for women with ID and their carers, and also the breast screening clinics; the role for this was believed to be the function of the new health facilitator.

I think maybe if there is more people coming in . . . and talking to women with ID and their carers and explain to them what it's about and how often they have it done and whatever. I think that would be a great help for them. (FG7)

#### *Training for all*

All participants highlighted that women with ID, family carers, day-care staff, residential staff, CIDN, GPs, practice nurses, breast screening nurses, radiographers and oncology staff required education and training on working with women with ID:

Training for everybody. Everybody really needs to know, from the GPs to day care staff, everybody who comes into contact with the woman with ID needs to know about this because it's not just our role as community nurses. It's anybody who is physically working with people with an ID. (FG3)

## **Discussion**

Findings from this study clearly illustrate that the CIDN and residential staff recognised the importance of breast awareness and attendance for breast screening for this target group. In terms of their knowledge, although the participants were able to identify a number of the key risk factors of breast cancer, other important risk factors were not recalled. Overall, the CIDN were able to identify a greater number of the signs/symptoms of breast cancer compared with the residential staff, albeit both groups failed to state all the indicators that arise concern in that staff may fail to detect abnormalities. The participants also indicated that many women with ID led sedentary lifestyles leading to obesity, another potential risk factor for developing breast and other cancers (Magnusson *et al.*, 1998).

As many more women with ID are living longer and living across a variety of community settings, they are therefore being exposed to a greater number of health risks; however, health promotion interventions are poorly developed for this population. Both family carers and staff working in ID need to promote healthier lifestyle choices that include eating a more balanced diet and participating in increased activity (Messent *et al.*, 1998; NHS Health Scotland 2004; Stanish *et al.* 2006; Melville *et al.* 2009). Development of such health programmes could also include greater understanding of the risk factors of breast cancer and importance of ongoing breast awareness and regular screening (Walsh & Heller 2002). For example, Symonds & Howsam (2004) in the UK developed a teaching pack for residential staff working with women with ID focused on breast awareness and how to prepare these women for breast screening. Evaluation of the educational resource was well received; however, no comment is made about whether up-take has improved or whether referrals for breast screening have increased.

Some of the CIDN provided health educational material in a user-friendly format explaining the purpose of the appointment and also the procedure; however, other CIDN and many of the residential staff were not aware that such material existed. These results reflect similar findings that highlighted a greater need for accessible cancer information and effective communication to people with ID and their carers (Gilbert *et al.* 2007; O'Regan & Drummond 2008; Melville *et al.* 2009). The National Institute for Clinical Excellence (2004) highlighted that cancer information should be freely available to all patients and carers; this places greater emphasis on ID staff, GPs, practice nurses, breast screening nurses, radiographers and also oncology staff to ensure such material is available for women with ID. Similarly, health promotion agencies also have a significant role to play in developing the appropriate material for this population (McIlpatrick *et al.* 2010). Mallinger *et al.* (2005) indicated that providing people with the appropriate information will allow for better informed decision-making, increased autonomy and enhanced psychological well-being.

Both the CIDN and residential staff reported mixed accounts of their perceptions of women with

ID experiences of breast mammography, although greater discussion focused upon the factors that inhibited these women not to attend for screening. As a result of low-literacy levels and poor communication skills, many of these women had limited comprehension of the need for breast awareness and regular attendance at the breast clinics (Jones & Kerr 1997, Tuffrey-Wijne *et al.* 2007, Truesdale-Kennedy *et al.* 2010). This dearth of knowledge was accompanied with negative emotions and attitudes pertaining to 'privacy, fear and anxiety, discomfort and pain and practical considerations'. The findings of this study reflect similar results undertaken by Sullivan & Hussain (2004) who also used a focus group methodology with residential staff to investigate why women with ID did not attend for a mammogram in Australia. The barriers identified were lack of information on screening, belief that the women with ID could not provide informed consent, fear and associated high anxiety levels and physical limitations to perform the test. The authors concluded that screening was too arduous for these women with severe/profound ID and proposed visual checks as an alternative.

The current authors also highlight that breast awareness via visual checks should be encouraged routinely and also in the absence of attendance at the breast screening clinic; although it is not as efficient in detecting breast cancer as a mammograph (NHS Cancer Screening Programme 2006). These women therefore become dependent upon family carers – normally older mothers – or residential staff to undertake these visual checks; however, this presents ethical challenges. Further research is required to examine the comfort levels of these family carers and residential staff when undertaking visual checks.

Gillings-Taylor (2004) reviewed the literature regarding family carers providing breast examination to their daughters/sisters with ID. One issue raised related to untrained family carers as well as untrained residential staff and CIDN undertaking the breast examination. This physical act could be purported to be 'abuse' in a population where informed consent would be difficult to obtain; this situation questions who should then perform the breast examination (Jones 2003; McEnhill, 2004; Kelsy 2005). Davies & Duff (2001) questions whether if both informal and formal carers do not

understand the importance of breast awareness and uptake of regular screening, then it is questionable whether they can fully inform the women with ID thereby limiting their understanding and capacity to give informed consent. The Nursing Midwifery Council (NMC) (2004) further highlighted that for any intimate procedures to be conducted such as breast examination, if informed consent is not obtained then this action could place the examiner in a position whereby they are accused of 'abuse'.

Where informed consent cannot be obtained because the woman may be unable to communicate and unable to understand and retain information, then a multidisciplinary group must act in the 'best-interests' of the individual (Tuffrey-Wijne *et al.* 2007). This study clearly illustrates that as the participants reported that some women have refused to attend for breast screening; therefore, there is a greater role for the CIDN and residential staff to educate the women to become more empowered to make a clearer informed decision. If written consent cannot be obtained, then the consent process can be guided by 'verbal' and 'behavioural consent' (NHS Cancer Screening Programme 2006).

Addressing these issues can be difficult as CIDN who do not perform breast checks could be seen as failing in their duty to care (NMC, 2004). The Royal College of Nursing (1999) offers some defence stating that only trained specialist nurses should perform breast checks; but many CIDN do not receive education in this area. Consequently, the potential risks have to be weighed against the beneficence of such actions. Guidelines need to be in place to clearly identify whose responsibility it is to perform the breast examination, supported by appropriate policies and procedures for ensuring the protection of the examiner (i.e. obtaining informed consent) (see Department of Health 2001, 2006; Scottish Executive, 2005; NHS Cancer Screening Programme 2006). While translating policy principles into practice guidelines to improve the health care access for people with ID has been a priority by many countries such as the Surgeon General Reports (2002) in the USA, a body of evidence suggests that the uptake of these policy and good practice guidelines have been poor (Mencap 2004; DRC 2006; McIlfratrick *et al.* 2010).

The limitations of this study correspond to criticisms of qualitative small-scale studies in general

(Parahoo 2006) in that the participants may be unrepresentative. This is an innovative study although the findings of this study are based upon a small cohort of CIDN and residential staff. Nevertheless, a number of checks were undertaken to ensure the issues identified by the participants were accurate, truthful and creditable (Slevin & Sines 2000). It was beyond the scope of this study to consult with women with ID and also their family carers about what they knew or understood about breast awareness and screening; future studies could focus upon these two areas.

### Conclusion

Research clearly shows that women with ID do not access the NHS Breast Screening Programme at the same rates compared with non-disabled women (DRC 2006). Despite the development of clear guidelines published by the NHS Cancer Screening Programme (2006) for women with ID, the findings of this study continue to show that access to breast screening services varies as a result of a lack of appropriate health educational material, health promotional activities, a continued lack of understanding of what to expect and also the possible consequences of screening.

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