

Supporting women with intellectual disabilities to access breast cancer screening: a healthcare professional perspective

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Cancer prevention has been identified as the most cost-effective strategy for cancer control. This should extend to all groups including women with intellectual disability, seeking to access breast cancer screening. The purpose of this study was to explore the role of healthcare professionals, such as primary healthcare staff ($n = 8$) and breast care staff ($n = 10$), on supporting women with intellectual disability to access breast screening in one region in the UK. A qualitative approach using focus groups and telephone interviews was adopted. Healthcare professionals identified that not only was it important that women with intellectual disability undergo regular breast screening but that they should have the same rights as other women to access breast screening services. While many varied risk factors for breast cancer in women with intellectual disability were noted, the level of cognitive functioning was clearly significant. Barriers to accessing breast screening included literacy problems, consent issues and physical health; practical barriers such as transport and timing of appointment; and barriers attributed to healthcare professionals, including staff attitude and lack of awareness and training. The participants identified the need to raise awareness and health promotion education not only for the women with intellectual disability but also for healthcare professionals, alongside developing more interdisciplinary practice.

Keywords: intellectual disability, women, breast screening, breast cancer, primary care, cancer prevention.

INTRODUCTION

Limited information exists on the incidence of breast cancer in women with intellectual disability, although some studies suggest that women with intellectual

disability share at least a similar risk of breast cancer with non-disabled women (Patja *et al.* 2001; Satgé & Sasco, 2002; O'Regan & Drummond 2008). However, as the life expectancy of people with intellectual disability increases, particularly with women living to an average age of 71 years (Bittles *et al.* 2002), this indicates that these women will survive to the age group at greatest risk of breast cancer (50–69 years) with a subsequent effect on breast cancer incidence. Evidence suggests that cancer accounts for around 16% of annual deaths in people with intellectual disability, and this is likely to increase unless

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needs are accurately identified and addressed (Cooke 1997; Patja *et al.* 2001). Various factors have been identified that are indicative of breast cancer risk among women with intellectual disability: limitations in cognitive functioning; limited mobility; poor diet; smoking; obesity, nulliparity and the long-term use of hormone-based contraception (Robertson *et al.* 2000; Stanish *et al.* 2006).

BACKGROUND

According to the World Health Organisation cancer prevention offers the most cost-effective long-term strategy for the control of cancer worldwide (WHO 2006). Austoker (1994) noted

cancer control encompasses the whole spectrum from prevention and early diagnosis to treatment and palliation. The key to the future of cancer control will be to establish multidisciplinary approaches to each type of cancer across this spectrum. (p. 517)

Furthermore, recent government policy documents have consistently emphasised that people with intellectual disability should have equal access not only to mainstream healthcare services (Department of Health 2001, 2006), but also to healthcare preventative services including breast cancer screening services (National Health Service Breast Screening Programme 2006). Despite this, however, it has been noted that people with intellectual disability are less likely to access health support and preventative screening (Lennox *et al.* 2001; Powrie 2001) and the uptake and use of breast screening services is poor (Sullivan *et al.* 2003; Wood & Douglas 2007).

While there has been a significant policy commitment towards a primary care-led National Health Service (NHS Executive 1994) and expanding health promotion-oriented work within the primary care sector (Adams *et al.* 2001), this has not been focused for people with intellectual disability. Alongside this there has been a general movement away from caring for people with intellectual disability in long-stay hospitals to the community, thus changing the way the health needs of people with intellectual disability are met. General practitioners (GPs), rather than hospital doctors, now oversee the health of people with intellectual disability, but often have little training or knowledge about the health needs of this population (Stanley 1998; Stein 2000; Phillips *et al.* 2004). This increases the vulnerability and risk for women with intellectual disability, as not only will they have difficulty in accessing health care but they also have reduced access to

staff that may have experience and knowledge working with people with intellectual disability.

A number of inconsistencies have been identified in primary healthcare services for people with intellectual disability (Disability Rights Commission 2005). One such reoccurring example is cancer screening (Lindop & Read 2000). Gibson (2006) identified a number of factors that have had a negative impact on accessing healthcare provision for this population, including poor access to GP surgeries, 'diagnostic overshadowing', inaccessible health promotion material, difficulties with communication, issues surrounding consent, lack of knowledge and awareness among healthcare professionals about the health needs of people with intellectual disability.

Therefore, healthcare providers may themselves be inadvertently regarded as a barrier towards breast screening uptake for women with intellectual disability. For example, a survey conducted by Stein (2000) asked GPs ($n = 64$) a hypothetical question what they would do if a woman with intellectual disability had not attended for mammography. Of the 45 GPs who answered the question, 28 said they would write or offer consultation, four said they would leave it, while 13 answered other, which included answers cited as discuss when seen next and discuss with support worker/carer. Stein (2000) remarked that discussions about such health matters are rare and highlights that 'leaving it be' is concerning given the risk factors such as nulliparity and obesity are greater in women with ID.

Despite the increasing knowledge and work around identifying the healthcare needs of people with intellectual disability, health inequalities still exist (Disability Rights Commission 2005). Therefore, issues around how women with intellectual disability are referred and invited for breast screening need to be explored.

METHODOLOGY

The overall aim of this study was to ascertain the healthcare professional's perspective on their role in supporting women with intellectual disability to access breast cancer screening. Specific objectives included exploring healthcare professionals':

- 1 Knowledge and awareness of breast cancer and breast screening;
- 2 Role and experiences of supporting women with intellectual disability access breast screening services; and
- 3 Perceptions of the barriers and solutions as to why women with intellectual disability access breast screening services or not.

Table 1. Description of participants

Primary care staff (<i>n</i> = 9)	4 General practitioners
	2 Practice nurses
	1 Nurse practitioner
	1 Primary healthcare advisor
	1 Specialist registrar in public health
Hospital breast screening staff (<i>n</i> = 9)	2 Superintendent radiographers
	5 Breast screening nurses
	1 Clinical co-ordinator
	1 Director of the breast screening programme

Given the dearth of information on this topic, a qualitative approach using both focus groups and telephone interviews was undertaken.

Participants

This study employed one focus group (*n* = 4) and a series of telephone interviews (*n* = 14) with two distinct groups of staff who volunteered to participate in the study. These included primary care staff (such as GPs and practice nurses) and hospital breast screening staff working within three Health & Social Care Trusts across Northern Ireland (see Table 1). The inclusion criterion was that the participants were required to have contributed to the care of women with intellectual disability who may have attended or refused to attend for breast screening. In total, there were 18 participants and data collection took place between May and September 2009.

Procedure

Clinical co-ordinators within each of the three breast screening clinics and a primary care group for a local cancer network were contacted, and asked to distribute the information packs and consent forms to potential participants. Each participant received an information pack outlining the purpose and nature of the study and expressed their agreement to participate through the return of a consent form to the research team. The one focus group undertaken was multidisciplinary, comprised of four participants: primary healthcare advisor, specialist registrar in public health, director of breast screening programme and practice nurse. As there was difficulty in recruiting a large enough sample to participate in focus group interviews, supplementary telephone interviews were arranged with both community and breast screening staff who had a role in supporting women with intellectual disability to access breast screening services. It was noted that the findings derived from both these data collection methods were similar and helped to reinforce the key messages.

Interview format

In order to guide a consistent flow to the focus group and telephone interview discussion, a semi-structured interview guide was developed based upon topics generated through the literature and the research teams' personal experience. This focus group format was structured into three sections. Section one examined the staffs' own knowledge of the risk factors (including signs/symptoms) of breast cancer in women with intellectual disability. Section two explored the healthcare professional experience of supporting women with intellectual disability to access breast screening services. The section three sought information regarding the barriers and also the solutions to why women with intellectual disability attend for breast screening or not. The focus group took place in a location convenient to the participants' place of work and lasted 50 min. The telephone interviews took place at the staff members' place of work, and lasted between 15 and 25 min.

Ethical considerations

The Office for Research Ethics Committee in Northern Ireland (ORECNI) granted ethical approval for this study and permission was obtained from the three Health & Social Care Trusts in Northern Ireland. Consent was sought and secured in writing from each participant prior to the focus group or telephone interview commencing. Assurances were given that no identifiable information about the participants would be included in the study. Each participant was given a unique identification code known only to the research team.

Data analysis

In order to ensure the rigour (i.e. accuracy, truthfulness and credibility) of the data collected, three steps were adopted (Slevin & Sines 2000; Parahoo 2006). First, recording the focus group and telephone interviews and transcribing the tapes verbatim assured consistent and accurate accounts of the participants' perceptions. Second, the transcripts of the interviews were subjected to a thematic content analysis using Newell and Burnard (2006)'s framework. Key points made by the participants were identified and assigned a colour code using the NVivo computer program (QSR International Pty, Doncaster, Victoria, Australia); similar codes were gathered together into themes and sub-themes. Third, to authenticate these key themes and sub-themes, the research team examined a random selection of the transcripts and disagreements

Table 2. Risk factors identified by primary healthcare staff

Risk factors	
WWLD ability to examine themselves	Diet (high fat)
Lack of awareness	Alcohol intake
Poor attendance for screening	Obesity
Poor literacy skills	Lack of exercise
Family history/genetics	Not breast feeding
Exposure to chemicals	Smoking
Environmental factors	Breast disease
Age	Use of HRT
Nulliparity (not having children)	Prolonged use of oral contraception
Menarche (early onset of periods and late menopause)	Oestrogen levels
Medication	

were discussed and consensus sought. The systematic approach used within the present study further increases the truthfulness and consistency of the qualitative findings, and thereby, enhanced the transfer value of the findings.

FINDINGS

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

Knowledge and awareness of breast cancer and breast screening

Across the interviews, there was a consensus that it is important for women with an intellectual disability to undergo regular breast screening, primarily for early detection and prevention. Participants felt strongly that women with intellectual disability should have the same rights as other women to access breast screening services.

Well they [women with ID] shouldn't be left out of the group. Its part of health screening and hopefully if anything is found or discovered that they get the appropriate management and treatment as necessary. Why should they be discriminated against the other group? (Practice nurse 1)

In terms of participants' knowledge and awareness of the risk factors associated with breast cancer in women with intellectual disability, participants demonstrated a good awareness of a number of risk factors (see Table 2).

It was evident that limitations in their cognitive functioning were one of the main risk factors for women with intellectual disability. This was related to their lack of

ability to self-examine, lack of awareness and understanding of breast care and prevention, poor literacy skills in relation to understanding the contents of the invitation for breast mammography and general poor attendance for screening.

I suppose some of the difficulties would be that perhaps their [women with ID] ability to examine themselves. Examination may be a problem whether that be because perhaps they would be unable to do it or they wouldn't understand the importance of it or what they would be looking for. (Breast care nurse 1)

Other risk factors associated specifically to women with intellectual disability identified by participants included the issue of 'not having children' and therefore 'not breast-feeding'; poor diet linked with lifestyle and the type of living accommodation and medical history linked with hormone-based medications.

Role in supporting women with intellectual disability access breast screening services

Two main roles emerged for health professionals (both in primary care and breast screening services) in relation to supporting women with intellectual disability to access breast screening services. These roles included: health promotion and providing education and support.

With regards to health promotion it was noted that a number of GPs reported that they would use opportunistic encounters to encourage attendance for breast screening and for overall health promotion activities. This encouragement to attend might include liaising with the Community Intellectual Disability Team or family. This is illustrated in the following excerpt:

We tend to see people with intellectual disabilities opportunistically mostly. . . . and I think that could be used as an opportunity to check with themselves and their carers that they have actually accessed screening, not only breast but also cervical. (GP 3)

For those staff working within the breast screening unit their role involved explaining the breast screening process to women with intellectual disability, offering health promotion to the women and their carer's before and after screening, and if a diagnosis of breast cancer is made to signpost women and their families to charities, other therapies and counselling.

Working in the breast screening programme, my role as a clinical nurse specialist is to educate the ladies, to be a support aid, to provide information about each step of the process so that they know exactly what is

happening. . . . So regardless whether they have a intellectual disability or not . . . we are the signposts, we are there for information, we provide advice, we provide support (Breast Care Nurse 2)

Perceived barriers to women with intellectual disability accessing breast screening services

A number of barriers were identified throughout the focus group and telephone interviews. These barriers included those related to personal aspects of the women with intellectual disability, those attributed to the carers and healthcare professionals and those related to practical considerations.

Barriers related to personal aspects of women with a learning disability

It was reported that the women's cognitive deficits, communication and level of understanding would pose as a barrier to them accessing breast screening services. The following comments were widespread among the participants:

I mean if they have intellectual disabilities and something comes in the post and they are not able to read, they may not even be aware that they have been invited to breast screening . . . also a lack of understanding of the procedure or of the purpose of the mammogram may be a barrier to the patient in that they really don't understand why they should be coming and don't realise the importance of it. (Breast Care Nurse 4)

In addition, the mobility and physical health of the woman with intellectual disability were seen as a potential barrier by some participants:

Some of our patients with intellectual disabilities also have major physical disabilities so they are wheelchair bound or their mobility is not great . . . so that might be a potential problem. (GP 1)

The issue of consent was frequently identified as a barrier for making decisions around breast screening and ability to give consent for the procedure and subsequent treatment.

The consent issue is something which would need to be considered because there are some patients because of their learning disability will not be able to consent and I think that is an issue. There are many patients we have in our own practice who don't want

to undergo breast screening and we respect that and it is how do we advise someone with intellectual disabilities to consent and if they can't consent, which is usually the case, who will consent for them . . . So it's a big area. . . . the consent issue has to be watertight. (GP 3)

Barriers attributed to carers

It was acknowledged among participants of the benefits and value of having someone to accompany the women with intellectual disability to their appointment and that the lack of carer support can be a potential barrier:

I don't think they [women with ID] would have ever gone through with any of the screening unless that they had the support of someone to communicate on their level and to advocate for them. (Focus group participant)

Carer attitudes were seen to be a potential barrier to breast screening for this target group as they may not wish their relative with intellectual disability to undergo screening as they do not see it as appropriate or as a priority:

The decision could be taken for them [women with ID] by carers and relatives may feel that it's not what they need, that it might cause them distress. So the decision may not necessarily be taken by the patient themselves. (GP 1)

Practical barriers

A number of practical barriers, such as transport and timing of the appointment were noted, which were seen to preclude women with intellectual disability access breast screening services:

. . . access to the screening unit or mobile unit where the mammogram is going to take place. So a transport practicality may prevent them from coming.' (Breast Care Nurse 4)'Maybe timing of appointments because a lot of these women need care in the morning. By the time you get them washed, their hygiene and get them fed, . . . and you know again with the distance and maybe having to be there for 9 am, you know, to allow an appropriate time in the afternoon to suit them. (Practice nurse 1)

Barriers attributed to healthcare professionals

Healthcare professional attitudes and experience of working with people with intellectual disability were identified as a barrier:

I would like to think that the staff and medical staff would think that these things are worth it rather than not worth it.' (GP 2)

'The general opinion that it was inappropriate for them, that they aren't at risk which is clearly not correct.' (GP 4)

It was recognised that the lack of staff awareness, exposure and training in working with people with intellectual disability indicated a need for more training:

Well its like anything, you can always improve on probably everything you are doing. . . . I don't know that as part of your training there is specific training on dealing with people with learning disabilities . . . it probably would be a good idea for us to undertake some sort of specific training or guidance from even another organisation on ways that we could improve what we are doing. (Radiographer 1)

A number of participants stated that healthcare professionals' lack of awareness of the intellectually disabled population within the community could be regarded as a barrier in accessing breast screening services and accessing targeted health promotion information and activities.

I think the main barrier really is health promotion-wise, I think we let them down by not being aware of the ladies within your population who have intellectual disabilities (Radiographer 2).

There isn't a specific resource that is focussed on women with intellectual disabilities to encourage them or enable them to understand the whole screening process. (Focus group participant)

It was frequently mentioned by the focus group participants how the GPs are the 'gatekeepers' of women with intellectual disability accessing breast screening services that can be a potential barrier:

There is a step before the invitations go out whereby the units send out the lists of ladies who are about to be invited to the GPs and they can make comments. . . . One of our concerns was that GPs were able to say don't invite them [woman with ID]. (Focus group participant)

On the other hand, it was recognised that since the GP knows the person with intellectual disability and their family well, it may be appropriate for them to indicate that they are not eligible for breast screening.

At times the GPs would be right. . . . the GPs probably knows the families for generations down the line

and sometimes rightly so, it wasn't in the women's best interests. (Focus group participant)

Solutions to women with intellectual disability accessing breast screening services

It was evident from discussions that there was a consensus among participants for the need for increased awareness and health promotion education not only for 'women with intellectual disability' and their 'carers' but also for all healthcare professionals, including what is traditionally perceived as 'community' and 'hospital' staff.

I think general awareness by all the professionals taking part from the breast screening staff to general nursing and medical staff. . . . It is something people have to take a positive view and say this is for learning disabled patients as much as anybody else and that they must be getting it and must be offered it. (GP 4)

From the discussions, it was noted that there was a need to promote more interdisciplinary working and integration including GP and breast screening services, linking with other support services.

I think it has to come from the bottom up. Right from the GP practices to right the way through, to the centre where they are having the mammogram and right the way through the screening unit as well (Breast Care Nurse 5)

There is a need to look at the whole process for a woman with a learning disability, what actually is out there?. . . . Probably it would be a good idea for a lot of people to get together maybe and try and see where it could be improved. . . . sort of inter-group discussions as to ways that the whole process could be improved. (Radiographer 1)

Having a multi-disciplinary approach from primary care, the radiography staff, you know, learning disability and identify what their learning needs are. (Practice nurse 1)

DISCUSSION

The findings from this study clearly illustrated that healthcare professionals considered that it is important that women with intellectual disability should have the same rights as other women and have access to regular breast screening. This is in line with policy direction emphasising that people with intellectual disability

should have equal access not only to mainstream healthcare services (Department of Health 2001, 2006), but also to healthcare preventative services including breast cancer screening services (National Health Service Breast Screening Programme 2006). Yet it can be argued that while policy and guidance call on healthcare services to be inclusive and supportive of people with intellectual disability, evidence suggests that the uptake of policy and good practice guideline in mainstream healthcare services has been poor (Mencap 2004; Disability Rights Commission 2005). The debates around the importance of breast screening for women with intellectual disability are important whenever we consider increasing longevity (Patja *et al.* 2001), alongside the increase in the incidence of breast cancer in the general population (Lalor & Redmond, 2009).

In terms of knowledge, participants were able to identify a significant number of risk factors for breast cancer in general and specific factors related to women with intellectual disability. Similar findings have been noted in the literature in relation to cancer risk among people with intellectual disability including lifestyle factors, such as diet and sexual activity; biological factors, limitations in cognitive functioning; and social factors such as limited financial income and limited participation in social activities (Mencap 2004; Emerson 2005; Stanish *et al.* 2006). It was found that cognitive functioning was identified as a significant risk factor for this group of women. This was related to cognitive deficits, communication issues and literacy. Communication has been identified as one of the most significant barriers to women with intellectual disability accessing screening (Bollard 2002). Lennox and Kerr (1997) noted that communication problems can reduce attendance at health screening services and become a barrier to seeking proper health advice if people are unable to explain their needs. This raises questions around the methods of communication for women with intellectual disability around breast screening and breast cancer. Alborz *et al.* (2003, 2005) identified a need for communication to be in an appropriate format. They argued that a person's ability to read appointment letters, information leaflets and consent forms cannot be relied on. This indicates a greater need for accessible cancer information and effective communication for people with intellectual disability and their carers (O'Regan & Drummond 2008; Melville *et al.* 2009). There is a need for appropriate resources to help women with intellectual disability understand the concept of screening as a preventative health measure (Broughton & Thomson 2000), as well as helping generic healthcare professionals to communicate this message effectively.

Barriers to accessing breast screening in this present study, such as personal aspects related to physical disabilities, consent issues, limited understanding, fear of the procedure and carers' attitudes, reflect similar findings previously identified by Sullivan *et al.* (2003, 2004) in Australia. The issue of consent was identified by participants as a barrier for making decisions around breast screening and ability to give consent for the procedure and subsequent treatment. It is acknowledged that obtaining informed consent presents practitioners and carers with difficulties. Consent is a complicated issue as the individual has a right to make their own decision but carers and health professionals have a duty to care (Nursing and Midwifery Council 2004). In Northern Ireland, someone who has a mild learning disability is considered as having the capacity to consent providing the information is provided in a format they can understand (DHSSPS 2003). It did appear that there was some ambiguity with healthcare professionals; therefore, more work and education is needed to help support health professionals' address this difficult issue of obtaining consent for breast screening.

The findings of the study indicated that the role of healthcare professionals in supporting women with intellectual disability to access breast screening services was focused around health promotion activities and providing support and education. It was found that many of the GPs considered that these health promotion activities were focused on opportunistic encounters. While these encounters could encourage uptake in relation to breast screening, questions exist around the effectiveness of such activities. This result is pertinent in light of the inconsistencies identified in primary healthcare services for people with intellectual disability (Disability Rights Commission 2005), the identified lack of knowledge among primary healthcare practitioners about the health needs of people with intellectual disability and the results of a study, which found that GPs tended to 'leave it be' if woman with intellectual disability did not attend for mammography (Stein 2000). Previous research has noted that some of the key reasons for not attending for screening include a lack of encouragement by physicians (George 2000), as well as the insensitivity of healthcare workers (Thompson & Pickering 2001). Therefore, there is a need to develop targeted health promotion activities and structured education programmes for these women, moving away from a reliance on opportunistic, unplanned encounters.

It was also noted that participants considered that the GPs played a key role as gatekeepers for women with intellectual disability being able to access breast screening and this was viewed both positively and negatively. From

a positive perspective, GPs were seen as being able to make an informed decision around the suitability of breast screening as they would know the woman and her family circumstances. From a negative perspective, however, this ability to make this decision could be viewed as paternalistic, removing the decision-making choices from the women. It has been noted that informed decision making about cancer screening requires that patients have a correct understanding of a test's purpose, benefits and risks (Denburg *et al.* 2005). Therefore, there has been a debate in the literature around the appropriateness of breast screening for women with intellectual disability (Satgé & Sasco 2002; Sullivan *et al.* 2003, 2004), particularly regarding women with ID with severe/profound, mental or physical disabilities and women with Down's syndrome. The counterargument is that excluding women from breast screening on the basis of the severity of intellectual disability is inappropriate, as women with intellectual disability have the same rights as any other woman to this procedure. These are key questions that healthcare professionals need to consider. However, given the limited evidence on the incidence of breast cancer in this population, it seems that more research is needed before debating whether or not screening is appropriate.

It was noted that the role of the GP and primary healthcare professionals for this population must be reinforced. GPs, however, often do not feel prepared to deal with the complex problems and consider that they lack necessary skills and knowledge to provide health promotion and screening services to this vulnerable group (Kerr *et al.* 1996). Therefore, it is vital to promote an interdisciplinary approach to the care of these women, recognising strengths and weaknesses of all professional groups. In addition, while community intellectual disability teams play a key role in the support, education and information on health promotion, they are often not informed about screening possibilities, its constraints and benefits. Training care providers is therefore also an important challenge. This vulnerable and marginalised population constitutes a growing public health problem.

The limitations of this study correspond to criticisms of qualitative small-scale studies in general (Parahoo 2006) in that the participants were self-selected and may not be representative of healthcare professionals in general. Furthermore, the combination of qualitative approaches (focus group and telephone interviews) used for practical reasons could also be viewed as a limitation. Nevertheless, a number of checks were undertaken to ensure the issues identified by the participants were accurate, truthful and credible (Slevin & Sines 2000).

CONCLUSION

Breast cancer poses a significant threat to the health of all women, including women with intellectual disability. Research indicates that women with intellectual disability are less likely to access breast screening, compared with the general population (Sullivan *et al.* 2003, 2004). Therefore, it is vital that these women are supported to access breast screening. The findings from the study show that healthcare professionals consider that they have a significant role in promoting this access and uptake of breast cancer screening. However, this role needs to be reinforced, supplemented by improved training, awareness and education, not only for the women with intellectual disability and carers but also for healthcare professionals. In addition, there is a need for improved interdisciplinary practice, across professional groups and sectors if breast cancer prevention and control is to be realised.

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REFERENCES

- Adams C.J., Baeza J.I. & Calan M. (2001) The new health promotion arrangements in general medical practice in England: results from a national evaluation. *Health Education Journal* **60**, 45–58.
- Alborz A., McNally R., Swallow A. & Glendinning G. (2003) From the cradle to the grave: a literature review of access to healthcare for people with learning disabilities across the lifespan. Available at: <http://www.sdo.nihr.ac.uk>
- Alborz A., McNally R. & Glendinning C. (2005) Access to healthcare for people with learning disabilities: mapping the issues and reviewing the evidence. *Journal of Health Services Research & Policy* **10**, 173–182.
- Austoker J. (1994) Cancer prevention in primary care: current trends and some prospects for the future – II. *British Medical Journal* **309**, 517.
- Bittles A.H., Petterson B.A., Sullivan S.G., Hussain R., Glasson E.J. & Montgomery P.D. (2002) The influence of intellectual disability on life expectancy. *The journals of gerontology. Series A, Biological sciences and medical sciences* **57**, M470–M472.

- Bollard M. (2002) Health promotion and learning disability. *Nursing Standard* **16**, 47–53.
- Broughton S. & Thomson K. (2000) Women with learning disabilities: risk behaviours and experiences of the cervical smear test. *Journal of Advanced Nursing* **32**, 905–912.
- Cooke L.B. (1997) Cancer and learning disability. *Journal of Intellectual Disability Research* **41**, 312–316.
- Denburg N.L., Tranel D. & Bechara A. (2005) The ability to decide advantageously declines prematurely in some normal older persons. *Neuropsychologia* **43**, 1099–1106.
- Department of Health (2001) Valuing People: a new strategy for learning disability for the 21st century. Available at: <http://www.archive.official-documents.co.uk>
- Department of Health (2006) Breast screening: the facts. Available at: <http://www.dh.gov.uk/>
- DHSSPS (2003) *Good Practice in Consent – Implementation Guide for Health Care Professionals*. DHSSPS (Department of Health, Social Services and Public Safety), Belfast, UK.
- Disability Rights Commission (2005) *Equal Treatment: Closing the Gap. Interim Report of A Formal Investigation into Health Inequalities*. DRC, London, UK.
- Emerson E. (2005) Underweight, obesity and exercise among adults with intellectual disabilities in supported accommodation in Northern England. *Journal of Intellectual Disabilities* **49**, 134–143.
- George S.A. (2000) Barriers to breast cancer screening: an integrative review. *Health Care for Women International* **21**, 53–65.
- Gibson S. (2006) Beyond a 'culture of silence': inclusive education and the liberation of 'voice'. *Disability and Society*, Vol. 21. No. 4.
- Kerr M., Dunstan F. & Thapar A. (1996) Attitudes of general practitioners to people with a learning disability. *The British Journal of General Practice* **46**, 92–94.
- Lalor A. & Redmond R. (2009) Breast screening for post-menopausal women. *Learning Disability Practice* **12**, 28–33.
- Lennox N. & Kerr M. (1997) Primary health care and people with learning disability: the evidence base. *Journal of Intellectual Disability Research* **41**, 365–372.
- Lennox N.G., Green M, Diggins J. & Ugoni A. (2001) Audit and comprehensive health assessment programme in the primary healthcare of adults with intellectual disability: a pilot study. *Journal of Intellectual Disability Research* **45**, 226–232.
- Lindop E. & Read S. (2000) Palliative care for people who have a learning disability: exploring the professional needs of qualified nurses. *European Journal of Oncology Nursing* **4**, 59–61.
- Melville C.A., Hamilton S., Miller S., Boyle S., Robinson N., Pert C. & Hankey C.R. (2009) Carer knowledge and perceptions of healthy lifestyles for adults with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities* **22**, 298–306.
- Mencap (2004) Treat me right! Better Healthcare for People With a Learning Disability. Available at: <http://www.mencap.org.uk>
- Newell R. & Burnard P. (2006) *Vital Notes for Nursing Research: Research for Evidence-Based Practice*. Blackwell, Oxford, UK.
- NHS Executive (1994) *Developing Purchasing and GP Fund Holding. Towards A Primary Care Led NHS*. Department of Health, London, UK.
- Nursing and Midwifery Council (2004) The Code: standards of conduct, performance and ethics for nurses and midwives. Available at: <http://www.nmc.org.uk>
- O'Regan P. & Drummond E. (2008) Cancer information needs of people with an Intellectual disability. *European Journal of Oncology Nursing* **12**, 142–147.
- Parahoo K. (2006) *Nursing Research: Principles, Process and Issues*, 2nd edn. Palgrave, Basingstoke, UK.
- Patja K., Pukkala E. & Iivanainen M. (2001) Cancer incidence among people with intellectual disability. *Journal of Intellectual Disability Research* **45**, 300–307.
- Phillips A., Morrison J. & Davis R.W. (2004) General practitioners' educational needs in intellectual disability health. *Journal of Intellectual Disability Research* **48**, 142–149.
- Powrie E. (2001) Caring for adults with a learning disability. *British Journal of Nursing* **10**, 928–934.
- Robertson J., Emerson E., Gregory N., Hatton C., Turner S., Kessissoglou S. & Hallam A. (2000) Lifestyle related risk factors for poor health in residential settings for people with intellectual disabilities. *Research in Developmental Disabilities* **21**, 469–486.
- Satgé D.C.L. & Sasco A.J. (2002) Breast screening should be adapted in Down's syndrome. *British Medical Journal* **324**, 1155–1156.
- Slevin E. & Sines D. (2000) Enhancing the truthfulness consistency and transferability of a qualitative study. *Nurse Researcher* **7**, 79–97.
- Stanish H.I., Temple V.A. & Frey G.C. (2006) Health Promoting physical activity of adults with mental retardation. *Mental Retardation and Developmental Disabilities Research Reviews* **12**, 13–21.
- Stanley R. (1998) Primary health care provision for people with learning disability: a survey of GPs. *Journal of Intellectual Disabilities* **2**, 23–30.
- Stein K. (2000) Caring for people with learning disability: a survey of general practitioners' attitudes in Southampton and South-west Hampshire. *British Journal of Learning Disabilities* **28**, 9–15.
- Sullivan S., Hussain R., Slack-Smith L.M. & Bittles A.H. (2003) Breast cancer uptake of mammography screening services by women with intellectual disabilities. *Preventive Medicine* **37**, 507–512.
- Sullivan S., Slack-Smith L.M. & Hussain R. (2004) Understanding the use of breast cancer screening services by women with intellectual disabilities. *Social and Preventive Medicine* **49**, 398–405.
- Thompson J. & Pickering S., eds (2001) *Meeting the Health Needs of People Who Have A Learning Disability*. Balliere Tindall, London, UK.
- Wood R. & Douglas M. (2007) Cervical screening for women with learning disability: current practice and attitudes within primary care in Edinburgh. *British Journal of Learning Disabilities* **35**, 84–92.
- World Health Organisation (2006) WHO Cancer Control Programme. Available at: <http://www.who.int/cancer/en/>