DONALD BEASLEY
INSTITUTE

KNOW WHO I AM:
WOMEN WITH LEARNING DISABILITY AND THEIR UNDERSTANDING AND EXPERIENCES OF WOMEN'S HEALTH SCREENING IN NEW ZEALAND

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First and most importantly, we would like to thank the women who shared their knowledge and experiences with us. Breast and cervical screening is a personal matter. The women who participated in this study showed great courage to share their individual stories. We hope that their wisdom can inform and change practice in ways that ensure women with learning disability enjoy full and equal access to the public health screening strategies that are available to their non-disabled peers.

We would also like to thank the individual's who supported a number of the women during research interviews. These people encouraged the women to take the lead in the interviews, but were ready to provide useful contextual information when asked. Their presence was extremely important for some women who looked for reassurance as they talked about this personal topic.

To the "key informants" – those individuals from the health and disability sector who had specific knowledge of this issue – we also extend a huge thank you. Their knowledge of and insights about women's' health screening in general, and the way in which women with learning disability engage with it in particular, was integral to this research.

Finally, Frozen Funds Charitable Trust must be acknowledged for making specific funding available to explore issues related to health for people with learning disability. Given the poor health status of people with learning disability in New Zealand, this represents an important action, and one which has the potential to make a difference in the specific area of women's health screening.

EXECUTIVE SUMMARY

Breast and cervical cancer are the most common forms of cancer for women in Aotearoa New Zealand. Although screening programmes have been implemented nationally to reduce the prevalence of deaths from these two cancers, both research in our country and those further afield indicates that a trend exists where women with learning (intellectual) disability are consistently less likely to participate in screening programmes in comparison to their non-disabled peers. Although the literature on overseas programmes identifies common barriers for this group of women, in the context of New Zealand, it is largely still the case that there is little reliable data on breast and cervical screening or the cancer rates amongst this particular group of women, and their uptake of the current screening programmes. The research and literature review of the current report was funded by the Frozen Funds Charitable Trust to further understandings of these inequalities in Aotearoa New Zealand. Insight on the topic of women's involvement in breast and cervical screening programmes was sought through: 1) exploring the perspectives of the women with learning disability themselves, and 2) exploring the perspectives held by health and disability professionals.

National Screening Programmes

There are two major breast and cervical screening programmes in Aotearoa New Zealand; the National Cervical Screening Programme (NCSP) and the mammography programme that operates under the umbrella of "BreastScreen Aotearoa".

The NCSP was initiated in 1991. Research indicates that since the programme's introduction there has been a reduction in the general population of cervical cancer mortality rates. Due to the causal relationship between the sexually transmitted virus, HPV, and cervical cancer, a woman's sexually active status is considered important for indicating her risk for this particular type of cancer. As sexuality activity forms a component of screening eligibility, identifying women who should be enrolled within the screening programme is not straightforward.

Aotearoa New Zealand's mammography programme was introduced in 1999 and is especially designed to address the more high-risk demographic of women in the 45 to 69 age cohort. Eligibility to participate in this screening programme is identified solely via age, making it easier to identify who should be within the programme.

Review of the Literature

This report locates the research within the existing evidence and literature available. Common barriers cited in the literature as being significantly relevant to women with learning disability and their entry to programmes include:

- Attitudes and perceptions, particularly those of third parties, whereby the women are perceived as being ineligible for screening and/or unable to tolerate the procedure.
- A lack of responsiveness on behalf of practitioners who do not provide adequate attention to a woman's needs (including communicative needs) or do not know how to respond to a woman's needs.
- The woman's sense of fear, pain, and anxiety associated with screening procedures themselves or their risk to having cancer found.
- The limited understanding and knowledge held by women with learning disability or their close supporters.

Some initiatives have tried to address the gaps in knowledge of women with learning disability or disability professionals through appropriate educational strategies. However, ultimately, there is little evidence available on the effectiveness of responses by primary health services and more research is needed to be increase confidence in the value of initiatives.

The Research Project

A team of researchers from the Donald Beasley Institute, Dunedin, and AUT University, Auckland, conducted research that positioned women with learning disability and their views and experience at the centre of the research, in keeping with the philosophies of phenomenology (Van Manen, 1990) and experiential thematic analysis (Braun & Clarke, 2013). To assist in developing a deeper understanding of the experiences of women with learning disability, the research also included interviews with health or disability professionals who either provided health service or supported women with learning disability in relation to their health. These interviews were incorporated within the research through an inductive experiential thematic analysis approach. This approach was suited for understanding informant's perspectives, views, and practices in a way that enabled data to be collated and subsequently examined across participants to identify patterns (Braun & Clarke, 2013). The study aimed to gain insight from these women and their health professionals in a way that could have potential to guide future efforts that improve the participation of their population of women in breast and cervical screening programmes.

Three key questions underpinned this research project:

1. What do women with learning disability understand about breast and cervical screening services (including the intent or purpose of such services and their relevance to them)?

2. How do women with learning disability experience breast and cervical screening (including the factors that have facilitated or impeded their participation in breast or cervical screening)?

3. What factors do health practitioners and disability service providers see as either facilitating or impeding the participation of people with learning disability in breast and cervical screening?

Participants were recruited with the support of learning disability service providers, who provided information about the study to their female clients.

Fourteen women with learning disabilities chose to participate in the study. They ranged in age from 26-66 years, with an average (mean) age of 47 years. Most of the women (n=11) identified as being New Zealand European and two women identified as being New Zealand European and Māori, and one identified as New Zealand European, Māori, and Pacific descent. The women were living in a range of situations in the Auckland region or lower South Island, including supported housing or residential care (with full time support), and independently (with varying levels of access to support).

The women were interviewed about their understandings and experiences of participating in women's health screening in Aotearoa New Zealand. Interviews were semi-structured to be responsive to the needs of individual participants. Some women opted to have their support persons present during the interview.

In total, five disability and health professionals took part in the research. These participants were purposefully sampled (selected) due to their expertise within both the disability sector or women's health screening.

Research findings

Analysis was conducted by means of thematic analysis of the transcripts and other data collected from women with learning disability, upon which three major themes were identified within the umbrella theme "It's personal – know who I am":

1. What I know: I need to know and understand
2. How I feel: I know it's important but I may feel nervous or uncomfortable.
3. What I may need: I may need support and understanding to access screening.

What I know

Although the women were clear and accepting about the purpose of screening, they indicated that they found it difficult gaining comprehensive and accessible information about breast and cervical healthcare, and even information that mitigated anxieties and fears. Like many New Zealanders, it was common for the women who participated in this research to have been impacted by cancer through family members and others in their close relationship networks. Similarly, family, friends, and support workers were typically the people who told the women about the danger of breast and cervical cancers but often provided little detail about screening processes themselves. However, women often experienced heightened anxiety from these conversations. Women also had a range of sources from which they received information on screening programmes, including: health professionals, support staff, or from information sheets and booklets offered by health centres or screening programmes. Despite the range of sources of information, the women expressed a lack of understanding about important aspects of screening or cancer itself, unsure of what they should look for in self-conducted breast examinations, and what screening entailed specifically. The women often expressed difficulty understanding text-based information, even those that claimed to be in Plain English.

How I feel

Many of the women who participated in this study enjoyed taking responsibility for their own health. They valued being treated in ways that were responsive to their feelings in both formal and informal interactions. They expressed that breast and cervical screening were uncomfortable and embarrassing (especially for women who had experienced sexual assault in the past), which subsequently impacted whether they felt they could ask questions and participate in their health care. For example, a significant number of women indicated strong negative feelings for their bodies and discomfort about self-conducted breast examinations. The women clearly identified that they needed to feel safe and secure and know that health professionals and disability service staff listened to and understood these feelings. It was indicated that this could be done by medical professionals being warm, respectful and comforting, with the patient while providing reassurance, continuing explanation, and information. The women made it clear that they appreciated where practice involved being responsive to their preferences for positive relationships with practitioners and other staff or other people who could accompany them to appointments. A few of the women in this study had experienced great pain and/or distress during cervical smears, and they indicated that the negative in these experiences were exacerbated by unresponsive and unsupportive care and the absence of a trusted person. It was also critical to the women that test results be conveyed directly to them in a timely, accessible manner.

Experiences with breast and cervical screening that were not sensitive to their feelings, fears, and anxieties made it harder for the women to cope with the screening procedure and also made it less likely that they would participate in screening procedures in the future.

What I may need

The women conveyed various ways in which they could be assisted to engage and remain engaged in health screening. It was very clear from the experiences of those women who had a close, supportive person accompany them to mammography and cervical screening appointments, that such a trusted person is of critical importance to facilitating communication in accessible ways and mitigating the women's anxieties. It was also noted that the women's confidence and sense of independence could be grown through increased access to information and the presence of positive relationships with health practitioners. The physical and financial accessibility of the screening service was also cited as being very important to the women. Furthermore, participants suggested that current advertisements and public health information is inaccessible for reasons of content delivery or the medium through which information it is distributed (for example, television). The women themselves suggested improving their engagement in screening programmes by using Easy Read and pictures of the procedure for explanatory ease, and educational group sessions for women with learning disabilities.

Interviews with the key informants, who included support people and health professionals, provided insights that were formed into five key themes: 1) the right to be screened; 2) the influence of screening programmes; 3) pre-screening preparation of women; 4) the screening process; and 5) preparing staff to support women. These themes are explained and evidenced through the use of verbatim quotes below.

The key informants expressed a philosophy that women with learning disability had a right to be screened but that this could be compromised by individual attitudes (for example, from family or staff) that create subsequent barriers for the women. They raised concern about women being obstructed from screening because of some health professionals exhibiting a lack of commitment to the screening of this group of women or, in particular, some family members stigmatising, or ignoring a woman's sexual history and activity.

Communication was essential to realising a woman's right to be screened. This included communication between a woman and her health professional, her specialised health clinics, her support persons, and her service providers who may offer "health check" initiatives that can largely focus on particular groups. Communication was identified as key to ensuring that women did not fall through cracks in the system when they may have needed information or enrolment. Key informants reported that in their experiences women who live independently are at increased risk of slipping through the cracks.

Pre-screening preparation was considered to be necessary to inform women and ease their possible anxiety, of which they considered disability support services and family to play a key role. Key informants emphasised the importance of clear and concrete information and rather than using one specific resource often utilised plain language and 'Easy Read' to personalise a range of resources to the woman concerned. Key informants placed emphasis on trying a variety of ways to convey information and gain consent that is continuous and informed.

Key informants also highlighted the importance of having the "right" person conducting the health screening, together with the "right" support person at their side, emphasising the development of positive relationships that were historical and/or engaging.

Personalisation of the procedure was repeatedly raised. Time was regarded as an important factor in preparing women with learning disability, gaining consent, and completing the screening procedure meaning that longer appointment times may be required. Working around the woman generally was considered important, considering factors such as the time of day, positioning during the screening process, being culturally sensitive, or providing multiple informative visits before actual screening.

Conclusion

To better understand the worrying gap that exists through the underrepresentation of women with learning disability in breast and, more particularly, cervical screening programmes, this research project sought to gain insight from women themselves to gain knowledge of their understanding and experiences about breast and cervical screening. Key informants were also interviewed to aid understanding about barriers and facilitators to women's participation.

It became evident that the women recognised the importance of screening and wanted to participate in ways that were 'compliant' with recommendations.

At the same time, the women also identified that discomfort and fear is a key issue for them in relation to screening; however, it was also conveyed that these feelings could be mitigated with responsive and caring practice. Key informants also emphasised the importance of responsive and caring practice through trusted people conducting screenings or being there as support people, adopting a personalised approach to the needs of the women to optimise the ease of their experience as much as possible. This is consistent with the literature, which recognises that unresponsive practice is a barrier in and of itself.

The interviewees also conveyed that cervical screening was often seen as more difficult compared to breast screening, due to the higher perceived embarrassment and discomfort, or the transparency required about sexual activity that was not easy to achieve when sex is often considered a taboo subject (particularly by family members).

It was also found that concern exists with regard to women living independently slipping through gaps because of systems and practice, thus compromising their participation in screening.

Overall, this study was consistent with the existing literature and augments it. This study's findings indicate that the following aspects can often work as barriers: attitudes of third parties, the level of responsiveness in practice by the health professional, important gaps in knowledge by women themselves and those around them, and the women's senses of fear, anxiety, and pain.

Recommendations

- Those working toward designing programmes or initiatives could look to improving the attitudes and perceptions, responsiveness, and skills of practitioners and support staff. They could look at exploring how barriers pertaining to assumptions on behalf of family, support staff, and medical professionals can be addressed and how awareness can be promoted about how people with learning disability can and do engage in sexual activity, and experience sexual abuse. Pilot programmes in New Zealand would be useful nationally and internationally to contributing to the larger evidence base on improving the participation of women with learning disability in screening programmes.
- Further research in Aotearoa New Zealand on this topic, particularly in the form of larger population studies and longitudinal research, is important to improving understanding on screening knowledge and uptake for women with learning disability;
    - There is space for further research to examine effective ways in which women with learning disability can be informed appropriately about national screening programmes, and breast and cervical cancer.
    - Further research that considers variables for this population of women in Aotearoa New Zealand could provide greater insight on the disparities within this group. This could provide comparative utility beyond the current disabled and non-disabled scope often employed. It would examine the population of people with disabilities in terms of other characteristics and memberships to other social categories (gender, sexuality, ethnicity) that comprise it. This could be particularly relevant to highlighting the health of haua (disabled) Māori in comparison to the rest of the disabled population.
    - It is important for further research to include the narratives of particular people so to include their voices in the national and international body of research, For example, there is opportunity to explore the experiences of

people eligible for screening who have high and complex needs and those who have experienced sexual violence.

CONTENTS

INTRODUCTION

This report details findings of a study designed to explore the issue of breast and cervical screening for women with learning disability in Aotearoa New Zealand.[1] Cervical screening and routine mammograms are health-screening strategies that have been implemented as a way of reducing the number of cancer deaths for women. International research has indicated that some women with learning disability confront multiple barriers when accessing primary health services (Barr, et al, 2008), and are less likely to participate in these screening programmes than their non-disabled peers (Osborn, et al, 2012). In the New Zealand context, the Ministry of Health (Ministry of Health, 2011) reported in 2011 that people with intellectual (learning) disability were 1.5 times more likely to receive cancer treatment or care than those without intellectual disability. Women with intellectual disability were identified as less likely to have participated in either breast or cervical screening; in the case of cervical screening, these women had an annual cervical screening rate of 33.6%. This stands in marked contrast to a rate of 70.6% for women without disability. The research reported here, which received funding from the Frozen Funds Charitable Trust,[2] was undertaken to explore this reported health inequality from the perspective of women with learning disability, and health and disability professionals.

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[1] The term "learning disability" is the preferred term of People First New Zealand and has therefore been used instead of "intellectual disability," except in instances where quoted literature or verbatim participants comments have used intellectual disability.

[2] The Frozen Funds Charitable Trust (FFCT) supports projects and initiatives that are run for and by people with mental health issues or intellectual disability. In 2012, FFCT called for proposals focused on improving health outcomes for people with intellectual disability. The current research was one of two proposals funded through this special funding round.

WOMEN'S HEALTH SCREENING IN THE NEW ZEALAND CONTEXT

Within New Zealand, the rates of breast or cervical cancer amongst women with learning disability is unknown; however, Hayes, Richardson, and Frampton (2013) report that breast cancer is the most common form of cancer for all women in the population, with Ministry of Health data indicating that 94.4 per 100,000 women were newly diagnosed in 2013 (Ministry of Health, 2015).

In contrast, 6.3 per 100,000 women were diagnosed with cervical cancer that same year according to the Ministry of Health (2011).

Cervical Screening

New Zealand has screening programmes in place for both breast and cervical cancer. The National Cervical Screening Programme (NCSP) was introduced in 1991 (Tan, Ward, & Thompson, 2015) with the subsequent success of annual death rates dropping to the figure of 1.8 per 100,000 of all women in 2012. As cervical cancer screening identifies pre-cancerous lesions as well as cancer, follow up with colposcopy can prevent cancer. Consequently, since the inception of the screening programme, the incidence of cervical cancer has decreased to approximately half of what it was. It must be acknowledged that for Māori women in New Zealand there is a higher incidence of cervical cancer, being twice that of women from all other ethnicities. It is not, therefore, surprising that it is this group of women are primarily focused upon, in comparison to any other specific group, by Ministry of Health initiatives.

Cervical screening is an invasive procedure requiring identification of the cervix in order to optimise the collection of appropriate cells. Women have to be able to cooperate with the smear taker by keeping still and tolerating the insertion of a speculum into their vagina, making the cervix visible. Women between the ages of 20 and 69 years, and who are or have been sexually active enter the NCSP when their first smear is taken, with few choosing to opt out (Tan, Jeffrey, Ward, and Thompson, 2015). Once in the programme, they will be recalled every three years through the service that took their original Pap smear. The NCSP includes a register that records the screening history of all women enrolled. Administrators of the register are able to contact both the smear takers and the woman to encourage continued participation in the programme or to follow up if concerns were identified. The need for close monitoring of individual women and the programme overall was highlighted through inquiries into inaccurate reading of smears in the past (Tan et al., 2015).

Whilst the NCSP is now seen as successful, recent development of a vaccine for Human Papilloma Virus (HPV) strains, which are considered the predominant cause of cervical cancer, along with better knowledge of the progress of how viral infection leads to cancer have raised questions about the best way to manage cervical cancer going forward (Tan et al., 2015). The current proposal is to change from a smear test that examines for cellular changes in the cervix to a primary HPV test that would identify the likelihood of developing cervical cancer. This new test, if approved, would be done every five years but would still require the identification of the woman's cervix and a swab being taken.

A key point regarding cervical cancer is the link with a sexually transmitted virus. In other words, it is only women who are (or have been) sexually active who are thought to be at risk of HPV-caused cervical cancer. It is, therefore, important for the woman or, in the case of some women with learning disability those supporting her, to have knowledge about her risk status. Whilst testing for HPV might lessen the frequency that women with learning disability need to have a cervical examination, it would appear that this test is currently similarly invasive to that used for smear taking. One study has identified that less invasive blind swabbing (where a speculum is not used) for endo-cervical cells was moderately successful with women with learning disability (44%) (Kavoussi, Smith, Ernst, & Quint, 2009). Although it was less than the 80% success rate when a speculum was used, the results suggested to the authors, that it was still reasonable to attempt a sample with women who could not tolerate examination with a speculum. Both less frequent testing with the identification of the presence or absence of HPV strains implicated in cervical cancer or accepting less accurate results might improve the likelihood of identifying cervical cancer for women who find the current procedures intolerable.

Breast Screening

The mammography programme was introduced into New Zealand in 1999 to address the high risk of breast cancer for women between 50 and 69 years with extension to include women between 45 and 49 years in 2004 (Morrell, Taylor, Roder, & Robson, 2015). In their analysis of the breast screening data from 1999 to 2011, Morrell et al. found a 34% reduction in breast cancer mortality for New Zealand women who were screened versus those who were not screened within the screening age group. Regular screening (30 months or less between screens) further lowered the risk of dying from breast cancer. Where screening had identified cancer, it was more likely to have been found early and therefore be more easily treated.

New Zealand's mammography programme is part of the "BreastScreen Aotearoa" service and is offered throughout the country in association with local providers (Ministry of Health, 2013). Women in larger centres are screened at specially designed clinics, whilst rural women can access mammography through a visiting mobile unit. Once women are registered with the mammography programme they should receive invitations to continue to be screened every two years whilst within the 45 to 69 year age group. As a national programme, BreastScreen Aotearoa offers a comprehensive approach including health promotion and education, the processes associated with screening, support and referral for women when necessary and information services. BreastScreen Aotearoa includes a range of professionals who support breast care from assessment, including mammography, through to treatment, including surgery.

Although there are some lifestyle factors associated with breast cancer (Hayes et al., 2013), there is not known to be any specific pattern, thus all women might be considered at risk and all in the 45 to 69 year age group eligible for mammography. A mammogram is an x-ray of the breast tissue that is displayed on a computer screen in the form of a black and white image (Mayo Clinic, n.d.). Mammography requires that the woman can remain still for a short period of time and tolerate the pressure on her breast as the two plates attached to the x-ray machine compress it. Tolerance of the process varies for all women; however, Wilkinson, Deis, Bowen and Bokbour (2011) suggest that women with learning disability find themselves particularly ill-prepared for the procedure.

In conclusion, both breast and cervical screening are relevant to women with learning disability. However, as is evident in the next section, there is little known about the uptake of current screening programmes in New Zealand by this group of women. Although both screening processes can be completed in relatively short time spans, the discomfort associated with them can mean that they are poorly tolerated and raise anxiety.

LITERATURE THAT PROVIDES DATA ON RATES OF SCREENING

Obtaining reliable data on breast and cervical cancer screening rates for women with learning disability is challenging. The larger population studies included in the following section, which would seem the most reliable, present a consistent finding that women with learning disability are less likely to be screened for either cancer than women without learning disability. The margin is greater for cervical cancer screening than it is for mammography. Among the limitations of the population-based studies is the ability to access accurate data that identifies women with learning disability. Furthermore, countries differ in the structure of their screening programmes, which can affect results as data for the studies is variably collected as to whether the women has never been screened or has not been screened within the timeframe that is recommended.

The only approximation of breast and cervical cancer screening rates for women with learning disability within the New Zealand context was reported by the Ministry of Health (2011). In this report a range of records held by the Ministry were examined for relevant information from which it could be assumed that the person had an intellectual disability. The final estimate of 0.7% of the population with an intellectual disability suggests it is not entirely accurate, given that the 2006 New Zealand Disability Survey suggested a prevalence of 1.3%. On the basis of those women who were identified as having an intellectual disability and were within the age range for the screen, 39.9% had mammography and 33.6% cervical cancer screening. In comparison, 48.7% of women in the general population had mammography and 70.6% cervical cancer screening.

To improve access to both breast and cervical screening programmes for women with learning disability within the UK, a register for those with learning disability has been instigated to enable data collection on their primary health outcomes. Using anonymised data from the Health Improvement Network, Osborn, Horsfall, Hassiotis, Petersen, Walters, and Nazareth (2012) drew on the primary care records to explore whether rates of cancer screening differed in people with learning disability compared to people without such a diagnosis. The authors found that, in 2009, women with a learning disability aged between 50 and 64 (the UK's programme age range for screening) were 35% less likely to receive a mammogram than women within the same age group who did not have a learning disability. Osborn et al. also found that in 2008 and 2009 women aged between 20 and 64 with a learning disability were 45% less likely to be screened for cervical cancer than their counterparts without a disability. Osborn et al. drew their data from across the UK. In contrast, Reynolds at al. (2008) collated data from the regions of Bury, Heywood-and-Middleton, and Rochdale and found cervical screening for women with learning disability was 27% in contrast to 76% for other women in that region. For their study, Reynolds, Stanistreet and Elton (2008) used General Practice databases and compared the cervical screening records of 267 women with learning disability with the records for 434 women without learning disability.

In Ontario, Canada, Ouellete-Kuntz, Cobigo, Balogh, Wilton, and Lunsky (2014) reviewed data for both mammography and cervical screening amongst a wider study of screening programme usage. Women with intellectual disability were identified through ICD-9 and ICD-10 diagnostic codes, which are used to determine eligibility for services in Ontario. A random selection of adults in Ontario between the ages of 18 and 64 years provided the comparison data. Total numbers for each test related to the screening programme parameters of that province. For mammography, and of the 7022 women with intellectual disability eligible, 52.2% had received the screen within the two-year timeframe, whilst 70.7% (n=402,589) of the other women were screened. In the three-year timeframe for cervical screening, 26,301 women with intellectual disability were eligible and 33.7% had been screened. That compared with 66.6% of other women (n=1,304,279).

In comparison to the above countries, where there appears to be a reasonable proportion of women without learning disability being screened, it is interesting to note that in Taiwan, of 4370 women with intellectual disability who were eligible, just 4.32% had mammography; however, the figure stated for women without intellectual disability was only 12% (n=not stated)(Lai, Kung, & Tsai, Wen-Chen, 2014). An earlier study in Taiwan had found women with intellectual disability were older when they had their first Pap smear than other women and, on that basis, younger women without intellectual disability were more likely to have had a smear. However, from 35 years of age the women with intellectual disability were more likely to have had a Pap smear. Of the women with intellectual disability in their study 22.1% (n=448) had a previous Pap smear. Of note, this study was based on self-report or report from a primary caregiver and the response rate to the 3283 mailed out questionnaires was 16.3%. That, and the characteristics of the women, including 58.1% being married, might suggest that the respondents were not typical of the cohorts in the above-mentioned population-based studies. Self-report of screening is more common in the qualitative studies. As Son, Parish, Swaine, & Luken (2013) note, a person's memory might differ to the records held by their medical practice on whether and/or when they were last screened, therefore care is required when interpreting data based on self-report.

A few studies have started to consider variables in the screening of women with learning disability. Osborn et al. (2012) included a deprivation index as a covariate and found that disparities in screening for both breast and cervical cancers were less pronounced in the more socially deprived areas and more pronounced in more affluent areas. For cervical cancer, women with learning disability were less likely to be screened than the general population if they lived in more affluent areas. For breast cancer, the rates of screening for people with learning disability showed less variation by social deprivation. Osborn et al., (2012) suggest that this lower disparity may be attributed in part to the possibility that services in more deprived areas are more acclimatised to providing care for hard-to-reach groups (p. 9). Similarly, Lacono and Sutherland (2006) from their survey of 2,540 people with intellectual disability found that those women living in community-based accommodation were more likely to have sex-specific screens, including mammography and cervical cancer, than those who lived with their family. Lai et al. (2014) explored a range of factors and concluded that higher levels of education, participation in other health promotion or disease identification (Pap smears) initiatives and a diagnosis of diabetes were associated with women being more likely to have mammography. Participation in other health promotion activities were also seen in Wilkinson et al. (2011), who identified influenza vaccination as making it more likely a woman would have mammography (OR, 4.38). In addition, their review of records held by the Massachusetts Department of Developmental Services for 2907 women indicated living conditions as being implicated. For the year that was studied, 53% of the women had been screened. Women with high activities of daily living needs were less likely to be screened when compared to other women on first analysis; however, for those with 24-hour support, this difference disappeared. Similarly, having a guardian meant women were less likely to be screened unless they were in 24 hour support. Having Down syndrome also made it less likely that the woman would have a mammogram, while family history of breast cancer and health coordination by a registered nurse (OR, 1.40) increased the woman's chance of having a mammogram.

Demonstrating racial disparities, Parish et al. (2013) noted that 29% of the African American women and 59% of White women, all with intellectual disability, received mammography screening in one South-Eastern State of the United States. The data for this study was collected from the women's medical records and the differences remained after controlling for variables in age, living arrangement, urban or rural community and severity of impairment. Findings of racial disparities raise important considerations for women with learning disability in New Zealand, where there are known poorer outcomes for all Māori women with regard to breast and cervical cancers.

One study attempted to differentiate disparities by disability severity (Horner-Johnson, Dobbertin, Andresen, & Iezzoni, 2014). While women with learning disability would be included in this group, not all women would have had a learning disability. Utilising a national sample of 120,147 women within the United States, the researchers analysed data files from self-reported interviews to separate out the likelihood of being up to date with breast and cervical screen for women with varying levels of disability. Among their findings it was noted that having complex limitations was more likely to mean that the woman would not be up to date with screening for either breast or cervical cancer. However, it is interesting to note that controlling for race/ethnicity, marital status, region, education, income and insurance status accounted for significant differences in breast screening but not cervical screening.

In conclusion, no country for which data was available, demonstrated a rate of screening for women with learning disability that equalled or was higher than that of the general population. Eligibility for mammography is primarily directed at age, therefore it is reasonably straightforward to identify women who should have the test. That ease of identification might contribute to why the difference in screening rates between women with learning disability and other women tended to be less than for cervical screening. It is more difficult to be certain about eligibility for cervical screening because of the link with known sexual activity. However, even with acceptance that fewer women with learning disability might be eligible, there is still a concerning difference between the number of women with intellectual disability who are screened versus other women. In the next section the literature that has explored some of the barriers to either screening tests is explored.

BARRIERS TO BREAST AND CERVICAL SCREENING

A small body of research has explored the barriers to mammography or cervical screening for women with learning disability (Biswas, Whalley, Foster, Friedman, & Deacon, 2005; Broughton & Thomson, 2000; Collins, McClimens, Mekonnen, & Wyld, 2014; Gribben & Bell, 2010; Lloyd & Coulson, 2014; Llewellyn, Balandin, Poulos, & McCarthy, 2011; McIlfatrick, Taggart, & Truesdale-Kennedy, 2011; Reidy, Denieffe, & Foran, 2014; Truesdale-Kennedy, Taggart, & McIlfatrick, 2011; Wicks, 2007; Wilkinson, Lauer, et al., 2011). In this section, the key barriers are firstly presented in relation to mammography and then for cervical screening. Inevitably barriers to one might be shared with the other test; however, there are some differences that are important to point out, especially given the difference in participation in these tests by women with learning disability.

Mammography barriers

The research presented in this section refers to mammography and not the more general breast screening, which can be undertaken as a physical self or other examination. Whilst some of the research has been based on the opinions of women with intellectual disability (for example, Barr et al., 2008; Llewellyn et al., 2011; Truesdale-Kennedy et al., 2011), other findings come from support people involved in the women's lives in some way (for example, Swaine, Dababnah, Parish, & Luken, 2013; Willis, Kilbride, Horsburgh, & Kennedy, 2015). Most of the studies share similar findings, although these might have been themed in different ways. In this section, the findings are drawn into key points around issues for the women at a personal level, system barriers, and service-related barriers. There are some cross-overs between these issues.

The woman's personal challenges

Most of the studies identified personal challenges for the women. These ranged from feelings of vulnerability about the procedure to ability to cooperate or attain the physical positioning required. While not all the studies used the term "vulnerability" Barr et al. (2008), Greenwood et al. (2014), Llewellyn et al. (2011), Sullivan et al. (2004), Truesdale-Kennedy (2011) and Willis et al. (2015) identified issues that could be seen to be related to the woman feeling vulnerable. For example, from the seven independent women with intellectual disability in Barr et al., vulnerability was expressed through their concern about having a family history of breast cancer, and not understanding the mammography procedure and what would be expected of them. Llewellyn et al. identified the role that friends have had in making the women feel more vulnerable by talking about the pain they might feel. Indeed, some women noted that having a physical disability meant that the procedure was likely to be more painful than it is generally accepted to be. In addition, for women who live with pain as a consequence of their physical impairments, it might be a choice to not undertake what they perceive to be a painful procedure. The women in Truesdale-Kennedy et al.'s study reiterated fear of the outcome of the procedure as well as suggesting that some women would be embarrassed by the need to undress.

Both women with intellectual disability and their support staff, family members or health professionals thought that the woman's intellectual impairment would preclude her understanding the procedure and its purpose (Greenwood et al., 2014; Llewellyn et al., 2011; McIlfatrick et al., 2011; Truesdale-Kennedy et al., 2011). The health professionals in McIlfatrick et al's (2011) study suggested that this would make gaining informed consent more difficult. In their earlier study Davies and Duff (2001) suggested that the relatively high (90%) uptake of mammography among the 30 individuals in their study who had received invitations might indicate that informed consent was not always given sufficient regard when they compared that to 23% of their respondents reporting a lack of information about mammography. Family members also worry that their relative will not understand the procedure (Greenwood et al., 2014). Despite that, in Swaine et al.'s (Swaine et al., 2013) study six of the eight eligible women had been screened, one was planned and only one family member refused based on her perception of her relative's ability to understand and cope with the procedure.

For women with both intellectual and physical impairments there can be difficulty both in terms of getting into the necessary position for the mammogram and in broader terms accessing the physical space (Barr et al., 2008; Llewellyn et al., 2011; Sullivan et al., 2004; Wilkinson, Lauer, et al., 2011). Whether some of these barriers are actual or perceived was highlighted in Sullivan et al. when they commented that amongst the social trainers they interviewed there was little knowledge of the way in which the mammography machine might be moved to adapt to the woman. Among the women with disabilities (not limited to those with a learning disability) that Llewellyn et al. interviewed there was some frustration when the person doing the procedure did not listen and work with them to get good positioning for their mammogram. As with Llewellyn et al., Barr et al. also interviewed women with a range of disabilities, including physical and visual impairments, with these groups being more likely to have difficulty accessing buildings and getting to the mammography unit. Such physical access difficulties were not emphasised in most of the other studies, although other aspects of access were, as illustrated below.

System barriers

In addition to personal barriers, the literature also identified barriers related to the wider context of mammography and the availability to women with learning disability. Across studies, the focus on lack of understanding tended to be with regard to the way in which mammography and the risk of breast cancer are communicated to the general population. The point that participants in these studies were making was that, for many women with learning disability, appropriate communication strategies might overcome lack of understanding. For example, a radiographer in McIlfatrick et al.'s study commented "…I think we let them down by not being aware of ladies within your population who have intellectual disabilities" (p.417). In their interviews with people who they identified as being key stakeholders (*n*=21), Collins et al. (2014) found confusion as to who was responsible for the health promotion messages associated with breast cancer being appropriately delivered to women with learning disability. In addition, they noted the challenge of communicating health promotion messages to people who have significant impairments.

Physical access to the building is important but conditions for access were shown to begin within the structure of the screening programme and the health system. For example, McIlfatrick et al. (2011) and Davies and Duff (2001) noted that the woman can be dependent on her general practitioner identifying her for mammography and this does not always happen. In Australia, the women in Llewellyn et al.'s (2011) research suggested that they were invisible to the system and, as such, did not receive the invitations to join a mammography screening programme, as was routinely sent out to other women in their age group.

For women who do receive an invitation, getting to the appointment can be a further barrier. Understanding the purpose, as noted above, is one problem; however, the information that is sent is inadequate in other ways. The women also need information on how to get to the clinic (Llewellyn et al., 2011) as they rely on either public transport or other people to take them. As noted by a respondent in McIlfatrick et al. (2011), consideration of the time of day that might suit can also be important if the woman has multiple care needs which take up much of the morning. In other words, a system that does not allow for negotiation of appointment times would be a barrier.

A challenge for the screening programmes is the conflicting information that women receive. For women with intellectual disability it can be difficult to sort through the information provided by the screening programme and the stories they hear from other women (Llewellyn et al., 2011) or advice from health professionals (McIlfatrick et al., 2011). The women with intellectual disability in Llewellyn et al.'s study suggested that they found it difficult to advocate for themselves in the health care system. If the staff at the mammography unit were not helpful they would be unlikely to express to them what they were feeling or where they needed help. Sullivan et al.'s (2004) participants identified that a painful experience when first screened meant that women were less likely to return for further mammography.

Service – or family-related barriers

As many women are dependent on services to assist them, it is not surprising that barriers can also exist at this level. Findings from Sullivan et al. (Sullivan et al., 2004) suggest that support staff who have had negative experiences of mammography are less likely to encourage the women they support to attend. The healthcare professionals interviewed by McIlfatrick et al (2011) also suggested that carers, including family, can put in place barriers by not understanding the need for mammography or worrying about the person's ability to cope.

Two studies have focused specifically on family perceptions of their family member's need for mammography (Greenwood et al., 2014; Swaine et al., 2013). Both of these studies relied on caregiver report. Swaine et al. (2013) had responses from family caregivers representing eight women in the age group for mammography. Of these eight women, two were yet to be screened, with just one citing that it was because of discomfort related to the screen. The other woman, who had just entered the age group for screening, was awaiting her caregiver to initiate the process. Two other caregivers did note that their family member had found the procedure unpleasant but there was no indication that they would not continue in the screening programme. Greenwood et al. (2014) interviewed 16 family members about their attitude towards the woman they supported receiving mammography. It should be noted that 12 of the women with learning disability being referred to in this study were under 40 years of age and just four of the relatives identified as having had a mammogram themselves. Of particular interest from this study was the meaning that mammography had for parents of women with learning disability. For some families, the choice to withhold screening was seen as tied up with their discomfort with the woman becoming sexually mature and with cancer being found and then having to make further decisions, such as those about treatment.

CERVICAL SCREENING BARRIERS

As noted in previous data, mammography screening rates for women with learning disability, while lower, are not dramatically different to rates for women without learning disability in countries where there is an established screening programme. The same is not true for cervical screening. Literature that has explored the barriers to cervical screening amongst this population identifies some of the same general themes as for mammography; however, there are some differences. This section provides an overview, with a focus on differences.

An earlier literature review by Watts (2008) that drew on the literature published in English from 1990 to 2007, provides a basis for the following points. The pre-2007 literature identified in the following sections was included in Watts' review and is detailed here for the purpose of understanding the barriers.

The woman's personal challenges

In the limited literature that could be found, there is general agreement that a primary reason for many women with learning disability choosing not to be screened for cervical cancer comes down to fear of the procedure being painful and uncomfortable (Biswas et al., 2005; Broughton & Thomson, 2000; Lloyd & Coulson, 2014; Watts, 2008). However, it is important to note that Biswas et al. also identified that, for 60% of the 160 women with intellectual disability who they initially counselled in an attempt to lift participation in cervical screening rates, screening was deemed to be inappropriate. Not being sexually active or having had a hysterectomy were among the reasons noted. For 18% of the women, previous painful experience provided a barrier to future screening. Furthermore, 5% did consent to be screened but were found to not be able to tolerate the procedure, with muscular spasticity being noted as one of the reasons. Although this is just one small study, it does highlight the differences in the population of women with learning disability compared to other women when considering cervical cancer risk and also the specific challenges that there might be for conducting the screen.

The 10 learning disability nurses interviewed for Lloyd and Coulson's (2014) study reported barriers to be the invasive and unpleasant nature of the procedure. Having supported women through cervical screening, they were able to recount times when women were not able to tolerate the procedure even with careful approaches to make it as comfortable as possible. In their opinion, it was fear that overrode the woman's attempt to relax, coupled for some with memories of earlier painful experiences.

Hypothesising whether or not a woman is likely to undertake cervical screening is related to her locus of control, that is, the degree to which she perceives she has some control over health outcomes, Wicks (2007) utilised adapted versions of standard questionnaires with 19 women. She found that locus of control made no difference to the likelihood of the woman being screened; however, knowledge about cervical screening did make screening more likely. In addition the 12 women who had been screened were more likely to perceive it as being of value. As this study was small, and given that the proportion of women (7 out of 19) who had not had a smear was different to documented prevalence data, the results from this study cannot be generalised to other women with learning disability.

System barriers

As with mammography, some women find it difficult to understand the information they are given about cervical cancer screening. In their review of literature about access to cervical screening for women with intellectual disability, Gribben and Bell (2010) emphasised the common finding that some or other aspect of the system failed. Incorporating the pre 2010 literature mentioned in the previous section, they identified attitudes and training to be inadequate, with a common concern that general practitioners or support people were making the decision about the woman's eligibility for screening or whether or not she would cope with the procedure.

General Practitioners are gatekeepers to screening programmes in many countries, thus, if they do not see that the woman is suitable for the screening programme, she will not be enrolled into the programme in order to receive invitations (Gribben & Bell, 2010; Watts, 2008). In the event that the woman was enrolled, a further barrier to her receiving or following up on the invitation came from support people. Decisions are often based on assumptions, such as that the woman is not and has never been sexually active.

As Gribben and Bell (2010) note, the process of informed consent itself seems to be a barrier for some health professionals to include women with learning disability in the cervical screening programme. This point was also noted in Watts' (2008) review. The nurses in Lloyd and Coulson's (2014) study identified that the combination of limited understanding with the likelihood of the procedure causing pain and discomfort to the woman was ethically challenging. Informed consent should be on the basis of people choosing for themselves; however, the literature suggests that health professionals might struggle with knowing how to approach the consenting process in a way that is understandable to the woman (Gribben & Bell, 2010).

When women do present for screening, both Gribben and Bell (2010) and, more recently, Lloyd and Coulson (2014) identify attitudinal problems amongst the staff. Attitudes include expectations that the woman will understand what is required without attempting to phrase instructions appropriately and rushed or impatient handling when carrying out the procedure. In common with the mammography literature and the health promotion literature, invitations and result letters for cervical screening fall short in terms of being accessible to women with learning disability but also to carers if they do not understand the implications for the woman they support (Gribben & Bell, 2010). As Broughton and Thomson (2000) noted, carers often lacked knowledge about cervical screening.

It is clear, therefore, that many of the barriers to mammography are repeated as barriers to cervical screening for women with learning disability. In the context of our health system the general practice to which the woman belongs is usually the entry point for either. However, within New Zealand there might be other entry points to the cervical cancer screening programme as women can present to other organisations, such as Family Planning, for a smear and it is the first smear that initiates the enrolment. No matter what the process, a common barrier to enrolment in either programme is other people identifying the woman as ineligible, or unable to cope with the procedure or to provide informed consent. In some instances, these barriers can be a result of lack of knowledge on the part of medical professionals or support people. Women with learning disability also identify barriers related to their understanding, including fear of pain and anxiety both about the procedure or what might be found. Having a positive experience of screening encourages future visits. Unfortunately a barrier can come as a result of the lack of responsiveness to the woman's needs on the part of the health professionals involved in the screen. The next section of this review addresses removal of barriers.

RESEARCH THAT HAS RESPONDED TO THE BARRIERS

While most of the articles that identify barriers to either mammography or cervical screening suggest strategies that might remove barriers for women with learning disability, few studies have attempted to evaluate strategies that have been used. In this section, the focus is on those studies, with the majority looking at means of improving women's knowledge about screening or ways to support them through the screening process. The effectiveness of most of these strategies remains uncertain, with limited results reported or the longer term impact yet to be evaluated. The review has not considered the wider results of annual health screens, which are known to improve screening rates overall, and, at least to some extent, are probably shifting the barrier of gatekeeping at the primary health provider level.

Improving women's knowledge and providing support

Responding to the identified barrier of limited knowledge amongst women with learning disability regarding screening, Swaine et al. (2014), Ramessur-Marsden et al. (2008), and Howieson and Clark (2013) tested interventions or developed tools to reduce the knowledge gap. A major problem for researchers designing studies that seek to identify knowledge development is the availability of suitable instruments to assess change in knowledge. The recent validation of a mammography preparedness measure by Wang et al. (2015) provides one instrument that might be useful in the future; however, for the studies that were found, more limited means were utilised to assess knowledge gain.

Swaine et al. utilised the Women be Healthy curriculum that had previously been developed in the United States and updated it to a Women be Healthy 2 version. They had three groups, a control (n=65), a group who received the first Women be Healthy curriculum (n=98) and a smaller group receiving the second version (n=35). An interview tool was developed for the purpose of demonstrating the effectiveness of the programmes. There were modest gains in overall knowledge for the Women be Healthy 2 programme that were not seen in the other two groups; however, limitations of the study mean that further research is required to be confident in the value of the programme. The researchers do point out that their study has demonstrated that women with learning disability can gain knowledge about screening through appropriate educational strategies.

Recognising the need to improve breast and cervical screening rates for women with learning disability in Wales, Ramessur-Marsden et al. (2008) piloted a teaching package aimed at learning disability professionals for use with women. One area in North Wales piloted the packages in order to determine their utility. Recommendations from the pilot have been used to further develop the resources, which are available at the following sites:

> Breast Test Wales, *Other Learning Disability Resourses,*
> http://www.breasttestwales.wales.nhs.uk/women-with-learning-difficulties
>
> Cervical Screening Wales, *Learning Disabilities,*
> http://www.cervicalscreeningwales.wales.nhs.uk/learning-disabilities

There would appear to be no published evaluation of the effectiveness of these packages in terms of uptake of screening. Similarly to Ramessur et al. but attempting to be inclusive of more screening programmes than breast and cervical alone, Howieson and Clarke (2013) developed resources for the use of people with learning disability and a wide range of support people. There is little detail in their report and, as they note, the impact on screening numbers was not known at the time of writing and searching for this review did not uncover further results.

As identified previously in the barriers sections, Biswas et al. (2005) used one-to-one counselling in an attempt to improve cervical screening rates for women with learning disability in their region of the United Kingdom. Learning disability nurses utilised tool kits and a care pathway to teach the women about the need for and process of cervical screening. The research was useful for identifying the reasons a number of women did not go on to have a smear but it was noted that the one-to-one counselling was time consuming and did little to raise the screening rates. The learning disability nurses who were interviewed for Lloyd and Coulson's (2014) study emphasised the benefit of a person with an established relationship preparing the woman with learning disability for cervical screening. Being able to take a flexible approach, having knowledge of the woman's ability to cope within potentially distressing circumstances and ensuring the primary health service is prepared were all believed to assist in a successful screen. In her earlier article, Wilkins (2004) had noted the need for an individual focus if cervical screening rates are to improve for women with learning disability. Her very labour intensive approach of one-to-one support and, if necessary, being the smear taker herself, would have limited application to the overall population of women with learning disability. However, these one-to-one approaches might be the better option for some women who remain fearful of the cervical screening procedure, yet are in the risk category of women.

Essentially the literature has focused on a change directly related to the women with learning disability; however, it was evident in the literature that explored barriers that change needed to address a wide range of issues. Apart from the introduction of annual health checks, which have shown subsequent uptake of mammography and cervical cancer screening (Lennox et al., 2007), there would appear to be no research that documents effectiveness of approaches aimed at improving responses by primary health services, families and support people, or screening services.

CONCLUSION

Women with learning disability do not participate in their country's health screening programmes for breast or cervical cancer to the same extent as other women in their community. The large population-based studies or reports from the screening programmes are important as a guide to participation of women with learning disability as the small qualitative or focused quantitative studies tend to provide screening figures different to the population-based data. In general, the smaller studies would suggest that more women are taking part, which might mean that these studies are missing important barriers for the hard-to-reach women who are not easily recruited into research. Most of the research reported in this review relied on recruitment through known disability networks.

Addressing the known barriers to participation in mammography or cervical screening is presumed to result in more women with learning disability taking part. However, the only rigorous study to date that has shown an increase in participation is Lennox et al. (2007), which reported this result as one outcome from the introduction of annual health checks. It is not clear whether that was a result of health professionals changing their thinking about the eligibility of the women, or simply that they followed the protocol as set out in the health check guidelines. Most of the studies that reported barriers to screening suggested the need to educate health professionals in order to change attitudes as well as increase their skills in communication. The structure of the mammography programme provides a reasonably clear pathway to reach the professionals who might benefit from education. Cervical screening, in contrast, involves professionals from a range of providers with much less cohesion making it more difficult to identify and reach those for whom education would be of benefit. It would be reassuring to think that health professionals could self-identify education needs. Considering the results of Lennox et al.'s research, the introduction of health checks as part of health policy for people with learning disability might be an effective way to initiate such self-reflection.

Addressing the education of women with learning disability appears to be a preferred strategy adopted in most of the smaller studies. Results from these studies provide some evidence that knowledge encourages participation in screening programmes. None of the studies have followed women over a period of years, which would be important to demonstrate whether or not women remained in screening programmes. Few education strategies have been evaluated for outcomes. There are a number of resources available on the Internet; however, these do not appear in published literature as having been evaluated.

Responses are needed at institutional levels to address the concerns that women with learning or other disabilities have regarding limitations in the health promotion material that the screening programmes disseminate to the public, quality of reporting results to the woman, access to buildings or transport, making adjustments to procedures to promote comfort. There does not appear to be any research addressing ways to respond to or evaluate these specific concerns.

Whilst this review has identified barriers to breast and cervical cancer screening for women with learning disability in other countries, there is no research that explores whether similar barriers exist in New Zealand. New Zealand women would appear to have participation rates that compare with the other countries that have researched barriers. However, it would be inappropriate to assume the barriers will be the same as the programmes do differ from country to country, as do the primary health services. The overall poor health outcomes for people with learning disability in New Zealand are a current concern for the Ministry of Health. It is therefore timely to seek information about the breast and cervical screening experience of women with learning disability, both to determine what the specific programmes might consider going forward and to identify how primary health services might respond to improve the screening rates for this group of women.

METHODOLOGY AND METHOD

This research was designed to explore the understanding and experiences of breast and cervical screening held by New Zealand women with learning disability. It also sought the views and perspectives of health and disability professionals with knowledge of women with learning disability and their involvement in and interactions with breast and cervical screening.

Three key questions underpinned this research:

1. What do women with learning disability understand about breast and cervical screening services (including the intent or purpose of such services and their relevant to them)?
2. How do women with learning disability experience breast and cervical screening (including the factors that have facilitated or impeded their participation in breast or cervical screening)?
3. What factors do health practitioners and disability service providers see as either facilitating or impeding the participation of people with learning disability in breast and cervical screening?

As mentioned in the introduction to this report, this research was significantly motivated by an identified difference in the rate to which women with learning disability are being screened for breast and cervical abnormality in comparison to their non-disabled female peers (Ministry of Health, 2011). To better understand this difference, we felt it was important to conduct the research in a manner that enabled us to capture the lived experience of women who had experienced, or had attempted to undertake, a mammogram or cervical smear. Our own approach as researchers aligned with the Frozen Funds Charitable Trust's philosophy in that we felt it was critical to have women with learning disability themselves at the centre of the research, discussing their experiences, and alerting us to strategies and approaches that create, or have the potential to create greater accessibility to women's health screening. To this end, the research foci was informed philosophically by interpretative phenomenology and experiential qualitative approaches. Phenomenology is a theoretical approach, well recognised within the broad field of qualitative research, which seeks to understand a particular phenomenon (in this case breast and cervical screening) from the perspectives of those individuals who have experienced it (Polit & Beck, 2017).

Experiential qualitative approaches and experiential thematic analysis (TA) similarly locates the focus of its inquiry on the views, perspectives, and practices of its participants in a way that validates and prioritises them as central to the research (Braun & Clarke, 2013). We also sought to extend the utility of the research by taking the opportunity to also capture the experiences and perspectives of disability and health professionals who either support women with learning disability in relation to their health or who deliver women's health screening services. It was anticipated that the collection of data from both sources would enable us to develop a deeper understanding of the likely reasons for the lower rate in which women with learning disability access women's health screening, particularly cervical screening, in Aotearoa New Zealand. Ethical approval was sought from and granted by both the Southern Health and Disability Ethics Committee (Reference 13/STH/94), and the Auckland University of Technology Ethics Committee (AUTEC).

RECRUITMENT

As with all research of this nature, participation was completely voluntary, and to ensure that individuals did not feel coerced into taking part, recruitment occurred through a "third-party" recruitment process. To achieve this, information about the study was disseminated to a range of disability service providers who had previously all agreed to act as a locality organisation for the research. The role undertaken by each locality organisation was to approach women who utilised their support to see if they would be willing to talk about their experiences of breast and/or cervical screening services. Each locality organisation shared plain language study information with women whom they thought might be willing to take part in the research, and helped the women (if required) to complete a Participant Interest Form that was sent back to the research team. The Participant Interest Form had the purpose of signalling a woman's interest in participating to the research team, thus triggering the first contact between the women and a member of the research team, and providing preliminary information about each woman. At this point, while the women had indicated strong interest, they were not obliged to take part. The research team arranged to meet with the interested women (individually and, sometimes, with their chosen support person) to explain more about the research and to reconfirm the women's interest in taking part. If the women were interested they proceeded to go through a consent process whereby the key components of their participation were discussed again, and their rights as a participant in research explained, including who to approach should they want to seek independent advice at any stage during the research.

Once these three recruitment steps were completed, the women proceeded to the interview phase of the research. It is important to note that third party recruitment can lead to difficulties, particularly as those undertaking the recruitment on behalf of the research team occasionally can misinterpret the purpose of the research and/or the criteria for participation. In the case of the current study, researchers were informed of several potential participants who, upon meeting, were either found not to be able to fully understand the topic of the research or to describe their experiences. Because of the design of this study, which specifically sought the knowledge and experience of women with learning disability about women's health screening, we judged it as inappropriate to include women whom we knew did not understand what the research was about. While we acknowledge that our exclusion criteria meant that such women did not take part in the study, it is clear that the breast and cervical screening activity of women with high and complex needs, or for whom verbal communication is particularly difficult, is an important focus for future research. However, to pursue such research, an alternative research design that did not rely so heavily on participant interviews would be required.

PARTICIPANTS

Women with learning disabilities: Demographic information

We interviewed 14 women with learning disabilities about their understandings and experiences of participating in women's health screening in Aotearoa New Zealand.

All women consented to participate in the study and most chose to have a support person with them during the interview. One woman consented to participating in the study on the condition that she was only asked about breast screening and not cervical screening; this was respected throughout the interview process and, accordingly, she was not asked about her reasoning for this. Some of the women who participated in the study had existing relationships with one of our research team (BMV) through shared connections and previous work.

With regard to ethnicity, eleven of the fourteen women identified themselves as being New Zealand European, two identified as New Zealand European and Māori, and one woman as of New Zealand European, Māori and Pacific descent. The fourteen female participants had an age range of 26-66 years, with an average (mean) of 47 years. Specifically, two women were aged between 20—30 years, five between 41-50 years, five between 51-60 years, one was aged over 60 years of age, and one woman did not choose to disclose her age. It is interesting to note that none of the participants in this study was aged between 31-40 years.

The women we spoke to were living in a range of situations, with varying levels of support. Some women were living in supported housing or residential care, with full time support, while others were living independently (alone, in flatting type situations or with a spouse/partner) with different levels of access to formal, paid support workers or disability support services.

Half the women were living in the Auckland region of the North Island of New Zealand at the time of their interview, and half were living in the lower South Island. The South Island women were from both urban and rural communities.

Disability and health professionals: Demographic information

As an additional component of the research, we also interviewed disability and health professionals (key informants) about their experiences supporting or providing health screening services to women with learning disability. These women were identified in two ways. In some cases the research team approached relevant disability or women's health organisations to inform them about the research and were then directed to relevant individuals within those organisations. In other cases, individual disability and health professionals who were known to have knowledge and expertise in the area of women's health screening in general, and/or the engagement of women with learning disability in women's health screening were approached and invited to take part in the research. In a small number of cases snowball sampling occurred whereby key informants alerted the researchers to other individuals who they felt would make an important and useful contribution to the research.

In total, five disability and health professionals took part in the research. In order to protect the anonymity and confidentiality of those individuals, we have chosen to not provide detailed demographic information about their designation or specific role. Three key informants worked in disability related roles and two were health professionals with significant experience in the area of women's health screening. Two key informants identified as being of Pacific descent while three identified as New Zealand European.

DATA COLLECTION

As previously mentioned, in keeping with the phenomenological and experiential philosophical approach taken in this research, data were collected through in-depth, semi-structured interviews (refer to Appendix 1A and 1B for Interview Frameworks). Each women with a learning disability participated in a 'conversational style' interview with a member of the research team. These interviews all took place in a location of the women's choosing (in their own place of residence or at the location of their service provider) and in a number of instances the women chose to have a support person present. In this situation care was taken to keep the primary focus on the woman and the story she had to tell about her experiences of breast and cervical screening. Sometimes the women asked their support person to "fill in gaps" (particularly related to the time that screening had occurred), and at other times directed the researchers to seek the answers to certain questions directly from the support person. This was particularly the case when the women were reporting that they found an aspect of breast or cervical screening personally challenging or difficult. In general, the interviews with both the women with learning disability and the key informants took approximately an hour to complete; however, in both participant groups, there were a small number of interviews that lasted considerably longer than an hour.

ANALYSIS

Phenomenological research can be analysed in a number of different ways but verbatim interview data is often analysed thematically in order to make meaning of individual experiences in a manner that has utility and transferability beyond the specific study population. In this case, we wanted the "lived experiences" of women with learning disability to inform a more comprehensive understanding of the knowledge that women hold about women's health screening, the issues that they feel impact on their access to screening, and what strategies might facilitate an increased uptake of population-based screening programmes. Further to this, we wanted to explore these same issues from the perspectives of disability and health professionals with experience in this area. For this reason, thematic analysis offered an appropriate framework for analysing the qualitative data generated through this research.

Specifically, the thematic analysis approach proposed by Braun and Clarke (2006, 2013) was utilised. Braun and Clarke advocate a multi-step process that ensures that researchers are both familiar with their data, and rigorous in their analysis. The individual steps are: reading and becoming familiar the interview data; identifying selective and complete codes in the data; identifying data-derived and researcher-derived codes; doing complete coding; and identifying patterns across the data. This analysis process was applied in the current study and underpins the findings presented in this report. All team members read the interview transcripts and two members of the research team taking responsibility for pre-coding and test-coding the women's data (AC) and also taking responsibility for the first coding of the stakeholder data (JC). All team members were involved in revising and confirming the thematic framework used to inform the analysis.

RESEARCH FINDINGS – THE EXPERIENCES AND PERSPECTIVES OF WOMEN WITH LEARNING DISABILITY

The central aim of this research was to explore the understanding of women's health screening held by women with learning disability in Aotearoa New Zealand and to learn about their individual experiences. As previously explained, 14 women with learning disability who had participated in cervical screening, breast screening, or both contributed data via qualitative interviews. Analysis of the data resulted in the identification of one central theme ***"It's personal: Know who I am"***. This theme pertained to the message that screening is a personal process because it is invasive and involves intimate areas of the body. But it also emphasises that screening is personal in the sense that it is highly related to women individually, their histories, needs, and senses of self. This overarching theme was underpinned by three subthemes:

1. What I know: I need to know and understand.
2. How I feel: I know it's important but I may feel nervous or uncomfortable.
3. What I may need: I may need support and understanding to access screening.

These themes offer both a structure for articulating the women's voices, and a framework with the potential to guide future policy and practice. Each theme is explained in detail below.

What I know: I need to know and understand

What does cancer mean to me and to those around me?

A significant focus of the research was on the understandings women with learning disability hold with regard to the purpose and the practice of breast and cervical screening. In order to do this, the women first talked about what cancer meant to them and to those around them. Regardless of the depth of each individual woman's knowledge about breast and cervical screening, all made the link between these population-based health initiatives and cancer. The theme **what I know** communicates the contributions that the women made about how they had come to know about cancer, particularly breast and cervical cancer, and the relationship between such cancers and women's health screening. It is important to highlight that not all of the women who participated in this study were aware that women's health screening was an intervention offered to all women, including women with learning disability. That said, like many New Zealanders, it was common for the women who participated in this research to have been impacted by cancer through family members and others in their close relationship networks. One woman had herself been treated for cervical cancer in the past. These understandings and experiences influenced the women's propensity to engage with screening services, producing both motivation and anxiety. Again perhaps reflecting the strong focus on breast cancer within New Zealand, the woman were significantly more informed about and focused on breast cancer than cervical cancer.

A number of the women told us about family or friends who had died of cancer or who had had treatments such as chemotherapy and mastectomy. In these cases, the women were motivated to engage in screening because they were hugely aware of what could occur if breast cancer was not picked up early enough. Other women noted that they wanted to avoid mastectomy as women who had undertaken this procedure had told them, *"it was not very nice to look at".*

What is breast and cervical screening and why is it important?

Family, friends, and support workers were typically the people who told the women about the danger of breast and cervical cancers. As previously mentioned, such conversations often heightened their anxiety and in some cases underpinned their motivation to engage in screening. However, despite being willing to tell women that they should be enrolled in screening programmes, these people were often less willing or able to talk in detail about the processes and procedures of screening, that is, what breast and cervical screening actually entailed. For this reason, there was diversity in terms of where and how women received information about health screening. In general, the women seemed to get most of their information about screening from health professionals, support staff, or from information sheets and booklets offered by health centres or screening programmes. It was common for women to describe their difficulty in deciphering screening information, even when supposedly written in Plain English. For many of the women, the available pamphlets contained too much writing, and not enough information about **who** requires breast and cervical screening. For example, one woman was confused about whether she needed to have a cervical smear, as she understood that only women who had a partner and were currently having sex should have smears. She said, "Cause they haven't told me about what's going to happen and why it's going to happen and stuff like that." Some women also talked about learning a little about women's health screening from television advertisements, "You don't want cancer, cancer can kill". It should be noted that no health promotion campaigns related to women's health screening have focused on New Zealand women with learning disability.

How I feel: I know it's important but I may feel nervous or uncomfortable

How I feel was a significant theme identified in the women's narratives. The findings generated through this research suggest that responsive and effective women's health screening requires recognition of each individual's past and current life experiences as these have the potential to impact on her ability to engage with the process. The following section elaborates on this notion by exploring the factors that were found to contribute to the women's overall sense of who they were, and what was important for other people to know about them in the context of women's health screening.

Talking about women's health issues and my body

Women's health screening is a personal process involving intimate parts of the body. Many women experience breast and/or cervical screening as uncomfortable or embarrassing. Similarly, the women with learning disability who participated in this research appeared to share this discomfort. It was evident that women with learning disability had diverse histories and their individual contexts influenced both the way in which they had come to learn about women's health screening in general, and how they experienced the actual procedures. Talking about women's health issues, especially sexual body parts and sex, was difficult for many of the women. Therefore, seeking to broaden their knowledge about women's health screening or to initiate a conversation with a health professional (or support worker) about a particular issue of concern were identified as being difficult. Again, as has been reported in research relating to non-disabled women, issues of gender came through in the interviews; a number of the participants described feeling more comfortable talking with a female health worker or support worker about women's health issues. As one women said, "*those are the parts I don't like talking to a man about*" while another commented that she preferred to talk to a female doctor about "*personal things."* One of the women also noted that she had a male support worker, which in her view made it *"kind of difficult to talk about that kind of stuff."*

For other women, however, gender was not the only factor that affected their ability to discuss issues related to women's health. Several of the women felt that it did not matter to them whether someone was male or female, but rather how that person treated them was the critical issue. One woman commented, "*I like him… he's a really nice doctor,*" while others shared the sentiment that they did not mind having a male doctor, it just "*all depends on who it is.*" This statement serves to highlight the importance that the women attached to the way in which health professionals interacted with them; warm and respectful interactions were critical to the women in this research feeling safe and secure when seeking (or receiving) information, screening or treatment for women's health related matters. Furthermore, it was important to some women that health professionals respected their health-related decisions (regardless of whether or not they agreed with them).

It is important to note, that the interviews with the 14 women who participated in this research clearly identified that they experienced a far greater level of comfort talking about breasts than talking about female genitalia. A number of women described that they asked for and received information about breast screening from their mothers, sisters, support workers, friends, and flat mates. Some also noted that these less formal channels were more accessible to them and enabled them to develop their knowledge over time, with one women noting that, "*you don't really go to the doctor to chat.*" What this woman was articulating was that she did not feel able to waste a doctor's time asking questions and seeking advice and that preparatory information was best accessed in other ways. This does raise questions about the accuracy of information that women with learning disability may be receiving through these informal networks. Given their specific learning needs, it is possible that women who receive women's health information in this manner may be at risk of being misinformed or of misinterpreting information.

Having opportunity to be responsible for my own health needs

While there was a great deal of diversity with regard to the extent to which the women who participated in this study engaged with their own health and health needs, it was clear that a number of the women enjoyed taking responsibility for their own health. Not unexpectedly, a woman's living situation strongly determined how she managed her interactions with the health system and health professionals. The women who were living more independently often showed the researchers files containing all their medical information, including information relating to women's health screening. These women typically attended medical appointments alone, and as signalled above, were also very keen to have their health related decisions respected. Through the interview process, however, it became clear that their independence did not necessarily mean that they were well informed about the health processes and procedures they were involved with.

Feeling like health professionals understand my fears

The women who took part in this research highlighted that they needed to feel as though health professionals and disability service staff listened to and understood their fears and concerns about women's health screening. This understanding was communicated, in the women's view, through talking, offering reassurance, giving information, and explaining what is happening at all steps of the screening process. Overall, the women valued being treated with care, respect and patience. The women liked being told what to expect, explanations of what was happening when it was happening, and knowing that their fears, concerns and preferences would be recorded in their medical records for *next time.* Continuity of care was also valued. For example, some women recounted that health professionals had remembered to warm or to use smaller cervical screening instruments. While it is likely that responsive practitioners will make such accommodations for all women, women with learning disability appreciated these thoughtful actions. One woman also valued both the continuity and the banter that was made possible by a consistent health screening team in her area. She stated:

> yeah just seeing the ladies there. The ones that I'm used to seeing and that. And they say, "Oh what are you doing back here? Go away now!" I says, ok then. They says; "no! Come back! We're only joking." Yeah, they talk to you all the time in there.

An understanding of screening as being a process was highlighted, with some women placing particular emphasis on the benefits of receiving reassurance throughout the procedure. One woman commented.

> I went in by myself; still frightened. The lady said "you're doing good [name]" all the time, and it was still a little bit sore when I came home too, you know?

The importance of communicating comfort or reassurance through touch was also prominent within the women's narratives relating to reassurance. One woman noted that her support worker squeezed her hand throughout while another described how she got herself through by holding onto her support worker or the nurse.

> Yes. That's what I like people to do. Talk to me through things, so I understand and not get scared you know? …And that's why I hold staff about their waist. And the nurse is really gentle. And they actually, the nurse and the caregiver, you know, whoever it is, tells me "it's nearly over [name], don't move, don't move." And you know, it helps me when they do that. When someone gentle lets me hold them. You know?

Conversely, women felt that they had had a negative experience during breast or cervical screening when their feelings were dismissed, or when they were not given adequate or accessible explanations of what would happen before or during screening. One woman described having her fears and anxieties about cervical smears dismissed by a support worker who told her that they only occurred infrequently. For this person, the relative infrequency of cervical screening did not make it any easier for her to contend with. Negative experiences such as these made it more likely that women would avoid breast or cervical screening in the future.

It matters who does (cervical) screening

There was quite a lot of diversity amongst the women with regard to who delivered their cervical screening. Some women received cervical smears from their General Practitioner, the Practice Nurse at their GP, or by Family Planning doctors or nurses. As previously mentioned, while the quality of the relationship between the woman and the person delivering the smear appeared to be more critical than their gender for most women, there was an exception to this. Women who had been sexually abused were reluctant to engage with male health practitioners.

> I always felt better [with] women checking me when it comes to things like that. As long as they are female I would feel ok about having my cervix checked – because I've had other things happen in the past. When I was young. That's one reason I wouldn't want any men or other people like that around me.

It is widely acknowledged that women with learning disability experience abuse at a higher rate to non-disabled women, therefore this is an important issue to consider when working toward achieving an increased participation rate in cervical screening for women with learning disability in New Zealand.

I need to know the results of my breast or cervical screening tests

Breast and cervical screening, like all medical tests, created a sense of anxiety within the women, thus making it critical that test results were conveyed to them in a timely and accessible manner. For women who lived in residential accommodation with significant assistance from disability support workers, results were often communicated back to the service, not necessarily to the women herself. In other cases, communication of results from the health service to the woman herself was done directly. This communication process allowed the women to ask questions of their GP or screening practitioner, and then discuss any further questions or queries with their support worker (who was also usually in attendance when results were communicated). This process was more successful in ensuring that women had all the information in a manner that was accessible to them. Women who lived more independently often learned about their test results without support. While the results were communicated directly in most cases, some women were unclear about their test results, whether or not they had ever had abnormal screening outcomes, or whether they had required follow-up treatment.

Anxiety and apprehension, though felt by the women, were not enough to stop them participating in breast and cervical screening. The women who knew about screening almost without exception, took it seriously and felt that it was something that was important to do diligently. Many said they would never ignore a letter that was advising them that they were due for a mammogram or smear, even when they were fearful about the process. One woman's comment illustrates the opinion of many noting: "*I've had everything I had to get done.*"

What do I know about breast screening?

Many of the women knew that from the age of 45 years they were eligible for population-based breast screening. Most described that this information had come initially from their GP, and then they received letters from Breast Screening Aotearoa to notify them when their screening was due. Women who lived more independently received this information directly, while women who lived in residential accommodation were more likely to be informed about their involvement through the service they were supported by. As previously mentioned, almost without exception, the women had made the connection between mammography and the prevention or detection of cancer. The following comment was typical of those ideas and opinions offered by the women who took part in this research when asked if they knew why women had mammograms.

> In case you get lumps and that, in case you end up with breast cancer. Because one of our ladies at work, two of our ladies at our job had their breasts removed.

Despite being reasonably clear and accepting of the rationale for breast screening, some of the women remained apprehensive about what they had heard was a painful procedure. This fear of pain meant that it was very important for the women to feel as though they knew what to expect. One woman said that she had been warned that the mammogram "*might not be pleasant*" she was thankful that "*they didn't leave me in the dark on anything*."

There was a great deal of variation in the way women experienced mammograms. Most described mammography as being "*a bit uncomfortable, but you know, it was just a squishy…not very pleasant… better than going to the dentist.*" Other women anticipated and experienced more significant pain.

> My breast got stuck in the glass, and that was hurting, it hurt… had to pull them off and it hurt.
>
> It pinched a nerve and I thought oh no; not doing that again, and I said not to do it again in the next one. I only had one check… pinch too hard…the thing went down so hard…I said no, don't, so they stopped.

Women made recommendations to improve the experience including making it more widely known that paracetamol prior to screening can reduce discomfort, being very careful when breasts are being removed from the plates, and warming up the plates. Additionally, explaining what is happening at every step in the process was a critical recommendation to ensure there were no surprises.

Do I need to check my own breasts?

Alongside discussions about mammography and the formal breast screening programme, we also talked with the women about breast awareness. While there is a wider debate within women's health about the utility of breast self-examination, many of the women knew they should check their own breast for signs of cancer, but they did not necessarily know **what** they should be looking for apart from breast lumps. Very few of the women reported that they knew about any of the other signs, symptoms or changes they should be looking for. Furthermore, despite knowing that they should be checking their breasts, they did not know **how** to conduct breast self-examination. All the women who had an awareness of breast self examination said they would tell their doctor if they found something they were unsure or concerned about. Despite this knowledge, however, analysis suggested that women who participated in this research had strong feelings about their own bodies, including their body image. While a few women were completely comfortable examining their own breasts, a significant number indicated that they were uncomfortable or embarrassed about touching or looking at their breasts, or were ashamed of them (due to their size). Another women said she had other priorities related to her outward appearance and therefore did not have time to examine her breasts. A further woman pointed out that she had a sexual partner, therefore is was more likely that he would observe changes in her breasts, leading her to believe it was unnecessary for her to check her own breasts.

What do I know about cervical screening?

Cervical screening was a harder concept for the women to talk about. Feelings of nervousness, embarrassment and fear were highly visible. Highlighting the fact that sexuality and sexual health is a taboo subject for many women with learning disability, for some individuals, their feelings of embarrassment began in the doctor's waiting room. Despite it being unlikely that anyone else would have any knowledge of the reason for their doctor's visit, a couple of women reported being self-conscious as they waited to be called into their appointment. This did not typically seem to be the case when the waiting occurred in the context of a Family Planning Centre. While for some women their nervousness was a result of a lack of knowledge, for most it related to the process of smear taking that they knew was central to cervical screening. Again, this fear did not typically stop women from attending cervical screening as they perceived it to be a critical health action. One woman who was in a sexual relationship believed that cervical screening ensured that anything unusual in terms of her sexual health would be picked up through this process.

Similarly to how women reported experiencing breast screening, there was also variation in terms of how they experienced cervical smear tests during cervical screening. A number of the women confirmed they were nervous and expecting pain or discomfort, but that it wasn't as bad as they thought it might be

> [It] was sweet, no problem; bit sore, like when she went in, because no one's, you know, been in before, that was the first time. But once it was done, and she had it, I was sweet as.

Conversely, other women were extremely distressed by cervical screening. One woman described the pain she felt during her last smear test. As her comments show, her distress was met with a comment that indicated to her that she was being told to "toughen up" and that she was over reacting.

> Sore. It was a nine last time. It was so sore; cause the thing that they open up the…they told me it's only once in a blue moon.

Another woman, who had previously been raped, reflected on the difference a caring and responsive health professional can make. She described having a smear soon after being raped during which the doctor inserted a "*huge*" speculum and "*she shoved it up me and I screamed and screamed and screamed.*" During a recent smear, the health professional was sensitive to her nervousness and used a very small speculum. "*They said it was a real baby… [support worker] said you could hardly see it, cause it was a baby one.*" This woman valued both the support that the health professionals involved in the smear offered to her, and the fact that her support worker held her hand throughout. For this woman, she was able to have a reasonably positive smear experience, despite having been sexually assaulted in the past, due to the actions of a sensitive and responsive health team, and the additional support of a trusted person.

What I may need: I may need support and understanding to access screening

One of the primary aims of this research was to identify what may assist women with learning disability to engage, and remain engaged with women's health screening programmes. The final theme, **what I may need**, addressed this aim. The women participants highlighted the critical role of both formal and informal support people.

It is important that I have support

Many of the women who had been accompanied to mammography or cervical smear appointments by a support person were very clear about the importance of support when attending appointments. Some women only required this support during their first mammogram and then were comfortable attending independently thereafter. For these women, their fear related to the unknown and once they had experienced a mammogram or smear, they felt more than capable to "*go it alone*" during future appointments. For the women who lived in supported residential contexts, it was common for them to look to trusted support workers or managers to accompany them. For women who lived more independently, husbands or family members were identified as providing moral support and reassurance when they were nervous about screening procedures. Having someone with them offered women reassurance and allayed anxiety. It was critical that whoever undertook this role was a trusted person, and one who could provide advice and guidance. In some cases, support people acted as interpreters who explained complex medical information and procedures. It is relevant to note that support workers were present in a number of the women's interviews, and frequently highlighted that health professionals were not always able to adapt health related information so that it was accessible to women with learning disability.

Once the women gained confidence, they were often very keen to be independent in their interactions with health professionals. Confidence grew through a combination of knowledge, and positive relationships, as evidenced by the following quote.

> Sometimes I go, the staff will take me. Sometimes Mum comes too, because sometimes, I have a really good relationship with my doctor. I get on really well with him. Him and I have really good conversations, get stuff out. Sometimes it goes really, really well. Um, he's such a cool doctor, I can just go and have an appointment by myself, and then he'll just talk to mum over the phone or something, or something like that. So there's little things like that, so I can sort of do it a little bit independently too.

I need information and services to be accessible

Women accessed breast and cervical screening in a range of settings. The critical factor for the women related to the physical accessibility of the environment as many of the women also had physical impairments. Mobile facilities, such as the rural mammogram screening services, were considered by some women with learning disability as being a more convenient and accessible physical environment. With regard to cervical screening, Family Planning was often the preferred health service for cervical smears as it was considered to be cheaper and more private.

Unsurprisingly, there was mixed awareness of advertisements. Some of the women were aware of the health promotion campaigns that related to women's health screening. However, even those who recognised the general topic of such advertisements, often struggled to decipher the content and messages being communicated. Television was not universally watched and reading was a challenge for many.

I have ideas that might help other women

Specific recommendations for increasing engagement in women's health screening made by the women who participated in this research were:

- Take a support person with you;
- Have information about breast and cervical screening translated into Easy Read;
- Ask questions with someone who knows about screening and who you are comfortable with;
- Use photos or videos to explain what happens during breast and cervical screening;
- Create opportunities to learn about women's health screening alongside other women with learning disability, for example at People First.

RESEARCH FINDINGS – THE EXPERIENCES AND PERSPECTIVES OF DISABILITY AND HEALTH PROFESSIONALS

Analysis of the data derived from the five disability and health professionals resulted in the identification of five key themes: the right to be screened; the influence of screening programmes; pre-screening preparation of women; the screening process; and preparing staff to support women. These themes are explained and evidenced through the use of verbatim quotes below.

The right to be screened

All of the key informants, regardless of designation, either directly stated or inferred that women with learning disability have a right to be screened for breast and/or cervical changes. Staff from support services positioned this right in terms of inclusion and empowerment as well as a right to the protection afforded by testing because cancer "*does not differentiate*." However, various comments made by some of the key informants who participated in this study suggest that not all health professionals or parents share this philosophical position on the right to screening or see the necessity for screening and that this can create barriers to access which can be difficult to challenge.

With regard to the preceding point, cervical screening would appear to be the more contentious of the two, with key informants indicating that some parents find it difficult to accept that their daughter might be sexually active. Furthermore, a number of women noted that, in some cultures, sex with a person with a disability would be considered taboo. Such an attitude has the consequence of ignoring the right to a sexually active life for the disabled person as well as hiding the potential for abuse. When the person has decided to have sex and chosen to not tell their parents, challenges arise for services as they support the person to access cervical screening. However, whilst there would seem to be a protective element to parents' beliefs about their daughter's sexual activity, a number of key informants suggested that doctors also struggle to acknowledge that women with learning disability might be sexually active. Various reasons were suggested for the doctors' beliefs. Contextual factors that were seen to have the most significant impact on doctors' views was when the a woman with a learning disability had high and complex support needs, was known to have lived most of their life in an institution, or was (or was assumed to be) a virgin.

Staff from disability support services could also make assumptions about the need for women to be involved in screening but these tended to relate to the difficulty they foresaw in gaining the woman's compliance or a quality screen. For example, one person commented *"a lot of women we support do have very high and complex needs, and possibly would not cope with mammography … a little bit of ASD … changes in the environments are very difficult"* [points drawn from a paragraph]. Furthermore, this same participant suggested that *"…when you've got somebody who's got musculo-skeletal contractures, and who can't straighten up, there is no way that you could get a proper reading from a mammogram."* However, practicalities aside, as one participant put it *"It's a bit easier with breast screening I suppose because … you just assume that everybody wants that*." This comment suggests that breast screening may be seen as less challenging for disability and health professionals because there is an easily communicated rationale for breast screening. In contrast, cervical screening requires disability and health professionals to engage with women about their previous and current sexual history to determine whether cervical screening should occur.

As previously mentioned, despite some evidence of resistance to screening, responses from the key informants would suggest that the right to screening is recognised to a lesser or greater extent by health professionals. More than one health screening provider commented on how the attitude of health professionals had changed over time. In one region it was marked by a shift in personnel, with new doctors and nurses recognising the right for women with learning disability to be screened and ensuring that any obstacles there might be were removed wherever possible. In another region it was noted that the patterns of referral for breast screening for women differed between doctors. The informant suggested that lack of General Practitioner referrals came down to historic behaviour, that is, it was not something done in the past, so why do it now.

However, even when the right to screening is acknowledged key informants felt it was not always clear as to who should initiate the screen or how to assess whether the cervical screen is necessary. Specialist providers of sexual health services, for example, can assume that a woman coming for contraceptive advice may attend her general practice for cervical or breast screening. One key informant suggested that discussions about the need for cervical screening often arise within the context of wider conversations about sexual and reproductive health that women have with their medical professional. This key informant held the view that, for women with learning disability, such opportunities for conversation about sexual and reproductive health might not present themselves. Furthermore, the key informants who held roles as health screening providers commented that it could be very difficult to assess whether a woman with learning disability has been, or is sexually active. Despite using plain language and pictures they can end up "*none the wiser*" when they do ask the woman. One person commented that questions needed to be as straightforward as, *"Has anyone put their penis in there?,"* because words like "partner" or "sex" were not always interpreted by the woman in the way that they would be understood by most adult women. Interestingly, she also commented that adolescent girls do not necessarily see a person with whom they have had sex as a "partner".

It is important to note that, while health and health screening professionals recognised that women with learning disability have a right to be screened, they acknowledged the important role that support people can take in insisting on those rights. Their perception was echoed by the responses of the support service informants (who typically held management level roles) who identified that they expected disability support workers within their service to ensure that the people they supported had access to the same rights and services as their non-disabled peers. To facilitate access to women's rights to screening, most of the disability support service informants drew attention to the relationships that they had established with their primary health providers. As one person stated, *"… I know that if I had a support worker that went in and supported somebody, and they didn't do such a great job and they weren't professional, I know that health professional would ring me."* This comment suggests that disability services see themselves as working in partnership with health services to ensure that the health needs of people with learning disability are met appropriately and effectively.

Influence of screening programmes

In addition to the national breast and cervical screening programmes, key informants noted the influence of the annual health checks coordinated through their services on uptake of screening, particularly breast screening. In the New Zealand context, there is no universal access to annual health checks for people with learning disability. Due to national and international evidence that points to positive health outcomes of comprehensive health checks, some New Zealand disability support services have chosen to implement their own annual health check programmes. There were two types of annual health check represented in the findings. One was an adapted version of the Cardiff Health Check protocol (Royal College of General Practitioners, 2010) and the other the Comprehensive Health Assessment Programme (Queensland Government, 2016). It did not appear to matter which of the two was used in terms of improving the numbers of women supported who entered into the National Breast Screening programme. One participant commented, in relation to process during the health screen, *"I think the health professionals in this area anyway …they're making it easier for them [women with learning disability] to access, because they actually ask them questions when they're there. They are checking; oh you are due for this…"* Within that region, the majority of the eligible women were receiving regular breast screening. In a different region, and within a disability service that had opted to use the other health check, it was noted by the other respondent that there had been a 20% increase in mammography referrals since the check was introduced to that service.

For women who chose not to have mammography or who were thought to be unable to cooperate with the procedure, annual health checks provided an opportunity for the health professional to examine the woman's breasts. As one key informant put it *"… at least they get a once-over. Our staff don't do breast checks on people."*

The most obvious gap in linking women with learning disability into breast screening occurred because comprehensive annual health assessment initiatives implemented by disability services were limited to those people with higher support needs. In other words, women living more independently were seen to be in charge of their own health needs and usually not included in the service-based "health check" initiatives. Key informants from disability services did not know whether or not these women took part in either breast or cervical screening as monitoring health was not part of the support they provided to these women.

Key informants from specialised sexual health clinics noted that there was the potential to miss opportunities to get people registered, both due to the relevance at the time of the visit and the assumption that they would be attending a primary care provider who would manage their enrolment in population-based screening programmes. Specialised sexual health clinics were more likely to focus on the purpose of the visit, rather than on linking women into population-based screening programmes that might not be relevant in the immediate future. If they did gain a woman's consent for cervical screening, that person would then be entered into the screening programme through their service and they would send out reminders. Once a woman was enrolled in the screening programme, the reminder letters or appointments appeared to be followed up if the woman was in residential care. No key informant was able to provide detail as to what happened for women living more independently. It was noted that one regional cervical screening programme offered transportation for women to attend appointments, if required.

There was geographical variation in the key informant participant group, with representation from both rural and urban centres. Breast Screening Aotearoa's service to rural areas was delivered via a mobile clinic and the rural women attended when it came to their area. Whilst some women managed the mobile clinic, access was an issue for some because *"the bus is small, it's pokey … it is the way it is set up …steps [are] …quite steep."* For women unable to manage the mobile clinic, their disability support service took them to the nearest fixed clinic if the woman was receiving a level of support from that service that incorporated health needs.

Pre-screening preparation of women

Key informants from disability support services noted that pre-screening preparation of women began well before attending an appointment. Such preparation was deemed necessary to ensure that women with learning disability were informed about what was going to occur, and as a way of minimising fear and anxiety. Most commonly, disability support services initiated pre-screening preparation; however, on occasion, family were also involved. One key informant provided the following example,

> … one lady here. Her sister took her to her breast screening when she had her own breasts screened … so when it came time for her … she knew exactly what was going to happen and what to expect."

In a service-initiated attempt to ensure a woman with a learning disability was appropriately prepared for cervical screening the informant reported:

> …I printed… copious amount of stuff off the internet, and I went and got the gadget… that they use to open up the vagina… and she went and met the nurse about 4 times to go through what was going to happen …

Even with this preparation it took a number of visits for the woman to be screened; the key informant noted that the one thing they had not prepared the woman for was the "noise" that happens when the speculum is opened indicating that all aspects of the procedure were confronting for the woman herself.

Utilising the range of plain language or Easy Read material that is available to educate women with learning disability about breast and cervical screening was a common pattern amongst the key informants from disability services. It was clear, however, that there was no one resource that was most consistently utilised. Most key informants commented that it was necessary to explore a range of resources to determine that most suited to the particular needs of the individual. Various pamphlets; the "Breast Book" (Love, 2010) from the New Zealand Breast Cancer Foundation; internet sites; and "Books Beyond Words" book series by *Beyond Words; empowering people through pictures* were all reported to be used. The characteristics that disability support staff looked for in resources included: plain language, appropriate photographs (one informant thought these better than cartoon-type drawings), and the scope to personalise the information for the woman. Just as the woman who took her sister with a learning disability to her own mammogram as a way of showing her what occurs and alleviating fear, it was not uncommon for the key informants to relate times when disability support staff had talked to the women about their own experiences, particularly with breast screening. In doing this, staff were reiterating the message that women's health screening was a part of life for all women and the procedures, however embarrassing or uncomfortable.

Initial cervical screening for women attending specialist clinics was less likely to have the benefit of prior preparation. The key informants who were practitioners in these environments relied on resources in the clinic, which included pictures and drawings that they then complemented with verbal explanation. While encouraging woman with learning disability to become familiar with the equipment used to perform a cervical smear was suggested by some as a way of decreasing anxiety, one key informant was ambivalent about letting the woman hold the speculum, suggesting it may put the woman off screening rather than being a reassurance. In addition to the challenge of providing information in a format the woman could understand within a relatively short time, these informants were also concerned about how the woman might interpret the invasive procedure:

> I don't think that cervical screening was ever discussed in that role [sex education and safety talks at school], so I wonder if that, in part of their mind is; is this a safe place to be doing this, I've been told I shouldn't do this in front of a stranger, but you're a stranger, so, should I?

This key informant went on to report that it was difficult to offer much useful support to an individual who may be challenged by the thought or the process of cervical screening, noting that the specialist service at which she was employed only offered group, rather than individual, counselling.

> … she doesn't do one-on-one education … we might express in the clinic that we have had someone come in [for a smear] and she will have a look at that and see; well we could do that as part of an education thing, either in a group home, or having a group of people come together to provide and use some resources …

Whilst this approach might not be of advantage in the immediate situation of preparing the woman for a smear, some informants did emphasise the need to get information out into the community so that women and their families can begin to think about screening. The point also made was that approaches to groups needed to be sensitive to their culture, for example:

> …its really important that when we do promote cervical screening to Pacific women with intellectual disability we give the right message … because a lot of the times Pacific people are put together as one, but no. We are totally different in every way … we don't want only two people [in the group] to get it because the message was created by … Palangi … [Pacific people] work together and they say this is the appropriate wording and information that people need to know, and also they are working together to make sure that the message is clear and informative.

Providing clear, factual, and concrete information was generally seen as the best way to prepare the women for screening. Although informants differed in the specifics, underlying their opinion was the need to make explanations accessible to the individual woman. One person put it, *"I think we need to go back to photos. I think that a lot of cartoon stuff that we use is not practical. To them it doesn't mean anything …".* Another used the "Beyond word" books, explaining, *"… they work well because we can write their own little stories with them as well"*. Even with the plain language explanations it can be difficult to assess the woman's level of or gaps in understanding if she is not able to communicate well with the health professional, as one informant reported, *"I have one lady in the service … we tell her what it is, she will go yes, yes, yes …we think oh … in actual fact she gets in there [mammography unit], she looks at it, and … off with her top straight away."*

The screening process

Issues of consent

Informants noted that the first step in the screening process was obtaining the consent of the woman. All were quite clear that screening should not occur without the woman's consent, indeed, if the woman objected part way through it was generally felt that the screening should stop. One exception to that came from a smear taker who felt that there was something of a dilemma. She said:

> … it is right that they can stop at any time. On the other hand, to not be able to complete it sets up a barrier for next time. So that sometimes, if the person's not in pain, I am inclined to encourage them to hang on a bit longer so that we can complete it, so that we can say, "look we did it." And the next time … it

> ought to be easier … rather than the idea that it wasn't able to be completed last time.

In contrast, another informant told of a woman who returned multiple times before a successful smear was taken. This suggests that the smear taker did stop when requested but that, by working through the issues with the woman, it was possible to respect her decisions and to eventually successfully complete the screen.

One smear taker noted the importance of understanding the individual woman's situation with regard to the consent process. As she put it …

> … when they have tried to get consent and they feel that they can't get adequate consent … to try to proceed, it would appear more harmful than beneficial. And I guess in a person in their 20s that is probably so, because the chances that they have got anything much going on is fairly low. But that shouldn't remain as time goes on. Into your 30s and 40s it is important …

In addition to age, there might be other signs that would lead the smear taker to be more assertive. As one key informant noted:

> … someone has been on depo and had persistent break through bleeding. I'd have to say there is a wee bit of pressure … to say; I really need to visualise this cervix to see if there is another problem going on. So sometimes there is a bit more pressure to be doing that with … taking smears, but it is more because, our problem is, rather than being part of a smear programme.

The consequence of not agreeing to screening was illustrated when one informant noted that, for a woman supported within her service, *"cancer had gone from her cervix right up through the lymphatic system … before it was picked up."*

Key informants recognised that capacity to give consent would differ for women with learning disability but thought that appropriate explanations with communication strategies that worked for that woman should be tried before a decision not to screen was based on inability to provide consent. Despite being assessed as having the capacity to consent, for some women the family might not agree to the necessity of the procedure. This situation was more likely to arise with cervical screening, although one key informant also mentioned it with reference to breast screening. Generally, with cervical screening it is because the family does not know the person has been sexually active and the person does not want family to know. For support staff, maintaining confidentiality in these situations is challenging, as one key informant put it:

> … in a round about way we had a chat with the family without disclosing anything, and then we had a chat with … the nurse beforehand so they had done everything they needed to do, and then later on it was decided that we would support the person to get … cervical screening done.

However, another participant explained the opposite situation where a mother brought her daughter for a smear but the staff did not believe that the daughter had the capacity to understand the procedure and were reluctant to proceed. Challenged as to how she would respond if there had been a history of sexual abuse, the participant acknowledged that in such a circumstance, if it were her daughter, she would want a smear taken. As one of the informants that takes smears noted, clarity around issues of consent can be difficult to achieve when the person is accompanied by a family member or caregiver who has decided the outcome of the visit in advance. With young people they might ask that the caregiver leaves the room, enabling a private discussion and assessment of consent; however, if the person with a learning disability has communication challenges the caregiver may be needed to assist them with understanding.

Whilst consent was seen as important, one participant noted a *"degree of consent*" as necessary to go ahead with an examination. Although not named as such by other participants, there was evidence of interpretation as to what might constitute consent for women with these procedures. For example, one participant suggested that in the case of some women, "*they really don't understand … sometimes I think that they are only agreeing to go along [for screening] because they trust us to be honest."* Other informants also mentioned "trust" both in terms of the consent process and as an important component of support during the screening process.

Support for women

Support during the procedures was often expressed in terms of having the "right" person. That applied both to the person doing the procedure and the person who had accompanied them. One of the smear takers noted that she would, at times, refer the person to another professional who she perceived of as having more specialised experience if she felt that would enable the woman to receive a successful smear. A support person noted the willingness of their local general practice staff to work with an individual woman, to the extent that, "*the nurse or the GP will come to the home and do that for her. We found she* *actually prefers it completed at home."* Regional differences were apparent with regard to cervical screening, with another informant noting that GPs do the smears and not the practice nurses, it being her interpretation that, *"they feel they've got a better relationship with the person."* Furthermore she did not think they would go to the person's home stating, *"I think they probably feel safer doing it in their practice rooms … ."*

Inherent in many of the descriptions of the "right" person was the relationship that had developed between the smear taker and the woman. For those going to General Practices, it was possible to work on the relationship over time. In contrast, where the woman went to a specialist service the relationship might be less secure, as one informant stated, "… *[a relationship over time is] probably least likely to happen in here… because we are not looking after the rest of their health."* The other informant from a specialist service provided an example of how this might be managed within such a service: *"There is one woman I'm thinking of in particular that we just happened to alert to smears … we know which doctor that she gets."* For both of these participants positive relationships were seen as the key to having the woman's trust.

Breast screening, whether at mobile clinics or the local fixed clinic, raised little mention with regard to the people doing the screen. The few comments made suggested the people doing the screens were supportive of the women although one informant thought that breast screening was often less successful than cervical screening for the women she supported because of the need to stand and tolerate the pain in the absence of staff. She said:

> … we don't always … have success, especially when it comes to mammograms, because it's a big machine, and getting them to stand long enough and to understand why … You probably get a better result with cervical screening because … staff are able to stay and support, talk and coax them through and be with them.

Informants from disability services emphasised the need to choose the "right" person to accompany the woman for either breast or cervical screening, *"it's about who has the right rapport, the right demeanour that suits the person … who they feel comfortable with."* Being perceived as the right person also entailed knowing about the person that they accompanied, *"There's no point putting someone on that's been employed for two weeks to go and take someone … To become familiar with the person … may take up to a 12 month period … especially if you are from a culture where … women's health screening is not talked about."* In one service there was a policy to postpone the appointment if, for any reason, the best support person was not available on the day. One informant included the sex of the support person, stating, *"It is inappropriate for males to accompany females for health screening, just as it is inappropriate for females to accompany males."* The support the "right" person offered ranged from being with the person throughout the procedure to waiting in the waiting room and taking them for a coffee or similar activity afterwards. In addition, one service had reviewed the documentation following a general health screen and noted that house leader or key worker involvement was more effective than just anybody from the service attending where the *"GP interaction is lower and the health screening referrals are lower".*

Although family were, at times, involved in decisions about screening, it appeared to be unusual for them to take their family member for screening if that person had a service supporting their day-to-day life. One participant noted that:

> we've got four [people] with welfare guardianship, they [parents] want absolute involvement with appointments … they want to go with staff support … but after a while people say; oh no, look, it's just the same old … you know, you can do it … they are learning to trust us as a service.

Allowing time

All informants mentioned time as a consideration, whether ensuring sufficient to prepare the woman, gain consent, or in the time taken to complete the screen. For the cervical screen takers that were interviewed the standard appointment times in their service are either 10 or 20 minutes. If cervical screen was not the initial purpose of the appointment, then it was difficult to include it as an opportunistic screen due to the extra time needed to explain the procedure to the woman. When the woman is prepared, the standard appointment is adequate. The sexual health service did have the capacity to offer longer appointments but that relied on the person at the call centre recognising or being told of the need. The practitioner can flag the need for longer appointments in the future but that raises issues of labelling, as the informant put it *"…do women want to be identified necessarily with a [learning disability]?"* One informant suggested that a 30 to 40 minute appointment might better suit women with learning disability in order to ascertain need and gain consent for a cervical smear.

For informants from services, preparing the women began well before screening took place, with the time devoted to doing so differing with the individual woman's needs. Informants from services emphasised that appointments should be set up "around the person." This included the time of day that best suited the person. They also recommended ensuring that the person would not be left waiting by checking that the practitioner was not delayed on the day. One informant spoke of the importance of being honest with the practice and noting when the person might not be able to wait for long without becoming particularly anxious. She commented that, for these women, if the practice staff "*know there is going to be a delay, they actually ring if we need to know.*" It also seemed to be not unusual for the service to work with the practitioners to slowly build a woman's confidence over a number of visits before a screen might be successfully completed.

Other issues of relevance to screening

Informants noted a range of points to consider when screening women with learning disability. These included choosing to position a woman on her side for cervical screening when she is particularly tense and facilitating the screening being done at home when the woman did not want to go to the clinic. Women with significant physical disability and particularly those with contractures were considered (by the informants) to not be suitable for breast screening. No informant was able to provide an example of how Breast Screening Aotearoa might manage such women with the default position of the service being that they have their breasts examined by their GP at the annual health check.

For both breast and cervical screening, informants mentioned the need to recognise the woman's anxiety might be associated with processes such as getting undressed or being physically touched.

One participant emphasised the importance of giving the woman feedback when her result came through and there was no abnormality. Neither smear taker remembered having had a woman that did have an abnormality, whilst they could talk about the process that was usually followed in such instances, they were not able to be specific about how that process would be adapted if the woman had a learning disability. However, both thought that it would need to be adapted to ensure the appropriate follow up given the range of possible actions dependent on exactly what had been found.

Two disability support people commented on management of women who had breast lumps identified through mammography. In one instance, the woman had a support person who had been through cancer treatment:

> This person had been a support worker for about ten years with this woman … [the woman] knew … [the support person] had cancer, and [that] she had worried about her … so [the support person said] remember when I was sick, this is what happened …

From the perspective of the informant, sharing the story with the woman allayed her fears and helped her to understand the treatments that were needed. More commonly, the women who were found to have an abnormality either had no cancer cells, or they required a lumpectomy rather than more complex surgery and treatment.

Preparing staff to support women

Of note was the invisibility of women with learning disability who live independently. The key informants who were smear takers recognised that they might not reach these women. Although a first smear puts the woman into the programme, including recall, there is little practical follow-up with one of these informants commenting:

> "I'd have to say it probably comes back … to a case worker … rather than the women themselves … some are good … and know that they have to come back, but some … other ones that would depend on the case worker …"

When support services were asked, however, it was clear that health needs were not part of their mandate in supporting women living more independently. The size of the branch was suggested to make a difference, so whilst in larger centres, informants had little knowledge of whether or not such women attended screening, one informant noted:

> "We're such a small branch, I know everybody quite well. The lady I was talking about … I'll just pick her up and take her out for a wine [after the screen]".

More notable from Auckland informants than those from the Southern region was the need to be conscious of cultural backgrounds. There were more people with Pacific and Asian family links and with religious affiliation to Islam and Hindi beliefs than they had previously. Informants noted a need to work with their own staff to develop their understanding of how best to support these women with health screening. In addition, first generation New Zealand born children from Pacific families were wanting the opportunity for independence that moving from the family home into a service might bring; however, their wishes were not always understood by their Pacific community.

CONCLUSION

Research on breast and cervical cancer has led to the implementation of population-based screening programmes in many countries, including Aotearoa New Zealand. While the rate of these cancers amongst New Zealand women with learning disability is unknown, there is nothing to suggest that this group of women is any more protected against these cancers than non-disabled women. Consequently, women with learning disability should be engaged in screening programmes designed to detect such cancers. In 2011, the New Zealand Ministry of Health released a report that confirmed that women with learning disability are under-represented in breast screening, and significantly under-represented in cervical screening. This disturbing finding motivated the current research. In order to contribute recommendations about how to reduce this worrying gap, we thought it was important to learn more about what women with learning disability understand about breast and cervical screening, and how they have experienced screening procedures. We also considered it useful to talk with disability service staff, and health screening and health promotion professionals to gain their views on why women with learning disability may not engage with breast and cervical screening.

This research was specifically designed to explore what New Zealand women with learning disability understood about breast and cervical screening services, and how they have experienced such services. It also sought to identify the factors that health professionals saw as facilitating or impeding the participation of people with learning disability in breast or cervical screening programmes.

The women who participated in this research communicated one strong and important message; breast and cervical screening is personal. The contributions made by the fourteen women with learning disability all spoke to the intimate nature of women's health screening, and reminded us that it is often difficult for women to feel comfortable talking about or showing sexual body parts; even in health contexts. The women were clear that their discomfort could be, and often was, reduced if support staff and health professionals took the time "to know who they were." The women in this research, like many women with learning disability, had often experienced critical life events that now impacted on their ability to take part in breast or cervical screening. Sometimes these events related to the illness or death of a family member or friend. In some cases this served to motivate the women to participate in screening but, at the same time, also increased their anxiety about the outcome of such medical tests. For other women, earlier experiences of sexual assault contributed to a fear of men and medical procedures including breast and cervical screening. It is important to note, that, however scared, the women who took part in this research all recognised the importance of women's health screening, and wanted to be 'compliant'.

This research showed that women with learning disability were diverse with regard to the level of knowledge that they held about breast and cervical screening, and their right to population-based women's health screening programmes. Despite this diversity, all the participants in this study recognised the link between cancer and the screening procedures they had been involved in. They were significantly more informed about breast cancer than cervical cancer, perhaps reflecting the emphasis on breast cancer in the wider community. While recognising the importance of taking care of their health, including engaging in health screening, the women in this research consistently oriented the research team to issues related to how they **felt** about such procedures. In particular, the sense of anxiety or discomfort felt when talking about sexual body parts was highlighted, as was, in many cases, a genuine fear of exposing their body in ways that were frightening or painful.

The women in this research held the opinion that barriers to breast and cervical screening could be significantly reduced through respectful and trusting relationships with disability support staff, health practitioners, and family and friends. All these people were seen to have a role in supporting women to understand the purpose of women's health screening, share their experiences, listen to the women's concerns, and make accommodations during the screening procedures. Women with learning disability showed a commitment to being active decision-makers with regard to their own health. They did, however, acknowledge that sometimes they required assistance to develop the health literacy and personal confidence to achieve this.

Disability and health professionals demonstrated a broader view when asked to consider the issue of engagement in breast and cervical screening and women with learning disability. These key informants highlighted that, in the first instance, women with learning disability have a **right** to be involved in screening; however, they also identified that not all health professionals or families share the same commitment to rights. Cervical screening particularly challenges some parents to accept their (adult) daughter as a sexual being. Furthermore, it was also felt that some doctors struggled to accept their patient with learning disability as having a right to a sexual life. While disability professionals were clear about rights, they sometimes made assumptions about a woman's ability to understand what was occurring during screening, that their physical impairment may be a barrier or that conditions such as ASD may make it difficult for women to accept the environmental conditions of screening.

While both the attitudes towards women with learning disability and the lack of commitment to uphold the rights of women to be engaged in screening were perceived as barriers, disability professionals identified general health checks as positively influencing the uptake of breast screening and, to a lesser extent, cervical screening. While this is an important finding, it is noteworthy that only women in some supported residential settings have access to funded or partially funded annual health checks. Women living more independently are reliant on population-based women's health screening programmes therefore, attention must be paid to ensuring such programmes are inclusive of and accessible to women with learning disability. It is also critical that a process of cross-checking occurs for women living independently to ensure that such women are registered with the appropriate health screening provider and that it is not assumed that someone else has assisted them to register.

Similarly to the women, key informants noted that positive screening experiences occurred when women were supported to prepare for their breast or cervical screening. Pre-screening preparation included a combination of accessible information, exposure to the screening environment, identification of possible triggers (e.g. noise) and, in some cases, watching someone else's screening procedure prior to their own.

With regard to the screening process, key informants noted that the issue of consent was sometimes a barrier to women's health screening as it was perceived to be difficult to obtain informed consent from some women. This gives rise to concerns about whether breast or cervical screening can or should proceed, and how to interpret a woman's individual response during the procedure as indicative of consent to be screened or to not be screened.

Key informants highlighted the need for women to have access to the 'right support during breast and cervical screening, echoing the voices of the participants with learning disability. Inherent to the 'right' support was the notion of trust. Given the deeply personal nature of these health procedures, it is vitally important that women with learning disability are able to traverse the often uncomfortable procedures of breast and cervical screening with a person they like, who knows them, and who is familiar with or attuned to the aspects of their life and life experiences that may influence their response to or engagement in the process. Central to this support is the notion of allowing time to listen to and understand women's fears and needs prior to screening, and to accommodate or adapt to these fears and needs during screening.

Because it cannot be assumed that all women with learning disability are connected with disability services, preparation and support for women's health screening cannot exclusively be assumed by disability services. Health screening services and their staff also need to understand and be responsive to women with learning disability as one particular group of New Zealand women who have the right to access population-based women's health screening programmes. As previously mentioned, it is concerning that no health promotion campaign has been designed to target women with learning disability, despite their reported reduced access to breast and cervical screening.

Limitations

This research has generated some important insights into the internal and external factors that may impact on the extent to which women with learning disability become involved in breast and cervical screening. It must be acknowledged, however, that only a small number of women with learning disability participated in this study, therefore the findings presented here represent a small contribution to this topic.

RECOMMENDATIONS

It is crucial that further research be conducted to increase the evidence base on women with learning disabilities in the context of Aotearoa New Zealand. Upon reviewing the literature on current evidence, it became clear that it would be useful for future research to focus on the generation of a body of reliable and larger population studies that provide information to women with learning disability, and the barriers they experience. Additionally, studies that consider variables in the screening of women with learning disability provide useful insights into possible disparities within the population of women with learning disability and advance policy and practice that have the potential to address the cancer rates in this population. Research conducted in other jurisdictions indicates that disparities do tend to exist within the population of women with learning disabilities. Additionally, current research has identified poorer health outcomes for Māori women in the general population with regard to breast and cervical cancers, therefore increased research on such variables for women with learning disability would be important.

With regard to initiatives, it would be valuable for longitudinal evaluation research to be implemented to ascertain whether educational initiatives are effective in the long-term for women with learning disability themselves. Due to the women's knowledge being identified as a frequent barrier, it would be useful for future research to identify ways in which health promotion material and information dissemination can be effective and accessible for women with learning disability. Research that explores effective information and information distribution appropriate to women with learning disability could develop NZ-specific guidelines and materials.

The current literature significantly identifies issues with the attitudes and perceptions, responsiveness, and skills of practitioners, which inhibits their ability to assist women in their participation in screening programmes. Education and training are suggested in the literature as means to address this barrier. Therefore, there is space to explore NZ-specific ways in which awareness can be spread to address the impact of attitudes and perceptions on good practice. As the findings of this report have signaled, an area off awareness that can be improved is with regard to the fact that people with learning disability can lead sexual lives and experience abuse that makes them eligible for cervical screening. Given that a wide range of individuals and services are involved in smear taking, future education activities need to encompass and respond to this diversity and can subsequently explore education with families, support people, the disability sector, the medical and primary sectors.

Given the exclusion criteria that were applied in the current study, it is clear that the breast and cervical screening activity of women with high and complex needs, or for whom verbal communication is particularly difficult, is an important focus for future research.

The experiences of sexual violence in the histories of these women were expressed as being significant to the distress that can manifest in screening processes, thus compromising their participation and likelihood of future participation. As a group who are regularly reported as experiencing high sexual violence (Johnson et al., 2000; McCarthy, 1999), the findings of this study suggest that further research on the screening barriers for women with learning disability who have experienced sexual violence could be of great utility to understanding how practice can be responsive to women.

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APPENDIX 1A

BREAST AND CERVICAL SCREENING

"HOW I THINK AND FEEL"

INTERVIEW FRAMEWORK: WOMEN WITH LEARNING DISABILITIES

Participant ID: _________________ **Interview date:** _________________

The interview framework is indicative of the subject matter to be covered. While this framework includes the intended topic areas, it must be noted that the researchers will be responsive to additional or unanticipated topics that participants may raise.

Demographic Information

This interview will begin with the collection of demographic information from each of the participants. *This includes collecting specific information about their disability status (e.g. related health and/or disability issues, educational placement and attainment; use of services; employment experience; family and community involvement; and income and living situation).*

Tell me about your life

- How old are you? Date of birth: _________________
- What is your ethnicity?

Which ethnic group, or groups, do you identify with (choose as many as apply):

☐ Māori	☐ Pacific Island	Please specify ____________________
☐ NZ European	☐ Asian	Please specify ____________________
	☐ Other	Please specify ____________________

- Where do you live?
- Who do you live with?
- Do you use a disability support service?
- Do you have a job?
- Are you on a benefit?

- What school did you go to?
- Are you in a relationship (do you have a boyfriend/girlfriend)?
- How is your general health? Do you have any illnesses?
- Do you have a physical disability/impairment?
- Do you have any hobbies, sports or special interests that you can tell me about?

This type of demographic information is important to later analysis processes. It is also an appropriate way to get to know each participant. This again assists with creating a positive research experience for the participant.

We have some specific questions to ask you today

Breast self-awareness

- Do you regularly check your breasts for any changes (like lumps or pain)?
- How did you know how to do that?
- How did you know what to look for?
- Have you seen or read anything about self-checks?
- How does it make you feel when you think about doing a self-check?
- How often do you think you should do a self-check?
- If you haven't done any checks by yourself, do you think you would ask anyone about how to do it?
- If you were worried about changes in your breasts, what would you do?
- Have you spoken to your caregiver or family member about checking your breasts?
- Have you ever found anything like a lump on your breasts that you talked to a doctor or nurse about?

General

- How do you feel about a health person checking your breasts or cervix?
- Is there any part of the examination that you get worried about?
- Have you ever not turned up to an appointment for screening? If so, why?
- Why do you think it is important to have breast and cervical screenings?
- Do you believe it is important to have regular checks? If so, why?
- Do you prefer to go to a screening appointment by yourself or do like to have a support person or friend go with you?

Breast screening

- Have you ever had a mammography/breast x-ray?
- Have you ever had a breast screening and the person who did the screening found something wrong with your breasts?
- If yes, what happened? How did you feel?
- How many times have you had a breast screening?
- When was the last time you had a breast screening?
- Where did you go to have the screening (eg. mammography centre or bus, GP)?
- Did you go by yourself? If not, who went with you? A family member, care worker?
- Was that person helpful?
- Were the staff respectful? Did they explain what they were going to do to you? Care for you if it got painful?
- Will you go back for another one? If so, when will you go back?
- Do you know anyone who has had a breast examination and the doctor or nurse found a lump? If so, what happened?

Cervical screening

- Have you ever had a cervical screening (smear test)?
- How many times have you had a cervical screening?
- When was the last time you had a cervical screening? Where did you go to have the screening (eg clinic, GP)?
- Did you go by yourself? If not, who went with you? A family member, careworker?
- Was that person helpful?
- Were staff respectful? Did they explain what they were going to do to you? Care for you if it got painful?
- Will you go back for another one? If so, when will you go back?
- Have you ever had a cervical screening and the nurse or doctor found something that they were worried about?
- Do you know anyone else who has had a smear test and they found something they were worried about? What happened?

Health promotion and information

- How did you find out about breast and cervical screenings?
- Do you talk with anybody about breast and cervical screenings?
- Do you want to know more about why it is important to have these checks?
- Have you ever seen anything on telly about caring for your breasts or how to check them for any changes?

- What would be helpful to you so that you can feel better about having these screening checks?

Thank you very much for talking with me today about how you feel about breast and cervical screening examinations. It was really good to hear what you had to say, and how we hope to be able to figure out ways to make these screenings less uncomfortable and embarrassing for you/easier for you.

If you remember something else that you want to say please give me a phone call, or if you decide that you don't want what you said to be part of the study, just let us know, and that will be fine.

Reminder: Check whether participant would like to receive a summary of their interview, a full transcript or would like to receive only a summary of the findings at the end of the research. This interview summary or transcript is private and may contain potentially sensitive information, therefore need to be mindful of checking whether participant has access to a safe place where they can store it. Also need to be aware to check whether they will need any support to read the transcript, and if they have someone who can support them to read through the information.

Notes from interview

APPENDIX 1B

BREAST AND CERVICAL SCREENING FOR WOMEN WITH INTELLECTUAL DISABILITY: "HOW I THINK AND FEEL"

INTERVIEW FRAMEWORK FOR KEY INFORMANTS

Participant:

Interview date:

The interview framework is indicative of the subject matter to be covered. While this framework includes the intended topic areas, it must be noted that the researchers will be responsive to additional or unanticipated topics that participants may raise.

Our over-arching research question for key informants is:

What factors do health practitioners and disability service providers see as either facilitating or impeding the participation of women with ID in breast and cervical screening?

Interview

This interview will begin with the collection of demographic information from the key informants.

This includes collecting specific information about their job title and description, their previous training and education in the areas of intellectual disability issues and health, their employment experience of these issues. [see 'Demographic sheet: Key informant interview version 1: January 2014']

General Questions

Health promotion and information

- How do you talk to woman with ID about breast and/or cervical screenings?
- What information do you think is useful for women with ID to know about breast and/or cervical screening?
- What are your thoughts about the reasons why women with ID tend not to attend screenings for breast or cervical cancer?
- Are there particular barriers to accessing these services for women with ID? If so, what are they?
- What do you consider would help encourage women with ID to take part in regular screenings?
- Do you perceive there to be an adequate level of understanding about the importance of regular screenings amongst the women with ID that you work with?
- How does your service ensure that women with ID are kept up to date with information about the importance of regular screening?
- Describe the appointment process for these women.

Questions for breast screening practitioners

Broad question to start:

- Tell me about your experience of working with women with ID.
    - How long have you been working in health screening?
    - How many women with ID do you screen on average in any given year?
    - Roughly what percentage of these women take part in a regular screening programme?
    - How long does it usually take to complete a screening? Does it take longer to screen a woman with ID?
- We know from the literature on breast screening for women with ID that there are a number of barriers that can make the experience of screening particularly difficult.
    - In your experience, Is there any part of the examination that some women with ID find particularly difficult?
    - What are your thoughts as to the reasons why many women with ID find breast screening difficult/unpleasant?
    - What do **you** find challenging about breast screening women with ID?

Other questions

- What do you think would encourage more women with ID to attend regular breast screening?
- How much does it cost for women to have a screening? Do you believe that cost is an issue for women with ID?
- If an abnormality is found during screening, what is the follow-up procedure in terms of supporting a woman with ID?

Questions for cervical screening practitioners

Broad question to start:

- Tell me about your experience of working with women with ID.
  - How long have you been working in health screening?
  - How many women with ID do you screen on average in any given year?
  - Roughly what percentage of these women take part in a regular screening programme?
  - How long does it usually take to complete a screening? Does it take longer to screen a woman with ID?
- We know from the literature on cervical screening for women with ID that there are a number of barriers that can make the experience of screening particularly difficult.
  - In your experience, Is there any part of the examination that some women with ID find particularly difficult?
  - What are your thoughts as to the reasons why many women with ID find cervical screening difficult/unpleasant?
  - What do **you** find challenging about screening women with ID?

Other questions

- What do you think would encourage more women with ID to attend regular cervical screening?
- How much does it cost for women to have a screening? Do you believe that cost is an issue for women with ID?
- If an abnormality is found during screening, what is the follow-up procedure in terms of supporting a woman with ID?

Questions for specialists in ID support provision

If not already covered within demographics, it may be necessary to ask for some details about the organisation – e.g. who are your main client groups? What is the role of the organisation in terms of working with women with ID? What is your role within the organisation? What is your background to working with women with ID in relation to issues of women's health?

- Do you believe screening to be of relevance to the women who access your service? Why/why not
- Who is responsible for supporting the women with ID who access your service to manage their breast and cervical health?
  - What role do the women themselves have?
  - What role do family/whānau or carers have?
  - Do you perceive there to be an adequate level of understanding about breast and cervical screening amongst the women with ID (and their families/whānau) that you work with? (Understanding meaning reasons for screening, and process of screening)
- What responsibility does your organisation have towards women's access to screening?
  - What do you see as your responsibility?
  - Can you tell me some more about your own role and experience of supporting women with ID to access screening services? (e.g. How do you talk to woman with ID about breast and/or cervical screenings?)
  - What values guide how you work with women with ID in your role – at an organisational level (e.g. policies guiding practice; how service ensures that women with ID are kept up to date with information about the importance of regular screening?); at a personal level (e.g. personal knowledge, awareness, or views regarding cancer and/or screening)
- In your experience, what factors act as barriers for women with ID from accessing breast screening?
- And what factors act as barriers to women with ID from accessing cervical screening programmes? (exploring if these are the same factors, or if they are unique to type of screening)
- In your experience, what factors support women with ID to access breast screening programmes?
- And what factors support women with ID to access to cervical screening programmes? (exploring if these are the same factors, or if they are unique)

- What do you consider would help encourage women with ID to take part in regular screenings?
- What information do you think is useful for women with ID to know about breast and/or cervical screening?

A big thank you to participant for their time – and also need to check whether participant would like to receive a summary of their interview, a full transcript or would like to receive only a summary of the findings at the end of the research.

Notes from interview

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