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Evaluation of Mammography Screening and Awareness Health Promotion Interventions Targeting Women with Disabilities: A Systematic Literature Review

Frances Irene Esquibel

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Frances Irene Esquibel

Candidate

Public Administration

Department

This thesis is approved, and it is acceptable in quality and form for publication:

Approved by the Thesis Committee:

Dr. Anthony Cahill, Chairperson

Dr. Uday Desai

Dr. Kun Huang

**EVALUATION OF MAMMOGRAPHY SCREENING AND
AWARENESS HEALTH PROMOTION INTERVENTIONS
TARGETING WOMEN WITH DISABILITIES: A
SYSTEMATIC LITERATURE REVIEW**

by

FRANCES IRENE ESQUIBEL

**B.A. POLITICAL SCIENCE,
UNIVERSITY OF NEW MEXICO**

THESIS

Submitted in Partial Fulfillment of the
Requirements for the Degree of

Master of Public Administration

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DEDICATION

Thank you God for all of your blessings and protection. This thesis is dedicated to the most important women in my life, especially my beautiful grandmother, mom, and my two loving sisters. To the most important men in my life, my grandfather, my nephews, and my amazing father. To the Rio Abajo Esquibel's and the people of La Joya de Sevilleta, both past and present. Lastly, I dedicate this thesis to all of the women whose voices so often go unheard.

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EVALUATION OF MAMMOGRAPHY SCREENING AND AWARENESS HEALTH PROMOTION INTERVENTIONS TARGETING WOMEN WITH DISABILITIES: A SYSTEMATIC LITERATURE REVIEW

By

Frances Irene Esquibel

B.A. Political Science, University of New Mexico

M.P.A., Public Administration, University of New Mexico, 2014

ABSTRACT

Research evaluating the effectiveness of health promotion interventions that aim to increase mammography utilization and or awareness among women with disabilities is extremely limited. The purpose of this thesis was to systematically review the literature that does exist, and examine the effectiveness and methodological rigor of various health promotion interventions, that aim to increase mammography utilization among women with disabilities. This thesis followed a five-step systematic review process: framing of the research question, identification of relevant work, extraction of relevant data on outcomes and quality, summarization of evidence, and interpretation of evidence. The sample consisted of eight articles that were evaluated and examined with the use of three tools: comparative matrix tool, quality assessment tool, and level of evidence pyramid. The results of the review revealed various health promotion intervention formats, among women with either a mobility impairment, intellectual disability, or learning disability.

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Chapter 1

Introduction

Breast cancer is one of the most common cancers in the world and poses a significant threat to all women, including those with disabilities. In the United States it is estimated that approximately 30% of women have a self-reported disability (Courtney-Long, Armour, Frammartino, & Miller, 2011). The American Cancer Society estimates that one out of eight women will be diagnosed with breast cancer in her lifetime, and one in thirty-five will die as a result of breast cancer (American Cancer Society [ACS], 2014). Breast cancer is the second leading cause of death for women in the United States next to lung cancer, and it is recommended that all women receive a mammogram annually starting at age 40 (ACS, 2014). There is strong evidence that mammography screening and clinical breast exams (CBE) may reduce mortality related to breast cancer, through early detection (Todd, 2012; ACS, 2014).

While the use of mammography may reduce breast cancer mortality, there are disparities among groups of women that result in its underutilization (Sabatino, Coates, Uhler, Breen, Tangka, & Shaw, 2008). According to Healthy People.gov (2014), women with disabilities are less likely to have had a mammogram in the past two years, compared to women without disabilities. The Center for Disease Control and Prevention (2012) estimates that between ages 50-74 only 78.1% of disabled women reported obtaining a mammogram, compared to 82.6% of women who were not disabled. In a study by McCarthy, Roetzheim, Chirikos, Drews, and Iezzoni (2006), empirical evidence shows that women with disabilities diagnosed with early stage breast cancer may have lower rates of breast conserving surgery, and higher mortality rates compared to non-disabled women. Depending on disability type, barriers related to underutilization of

mammography among disabled women are often related to finances, environment, lack of physician referral, and lack of awareness (Courtney-Long, 2011; Barr 2008; Todd, 2012).

In general, people with disabilities are more likely to experience delays and difficulties in accessing health care (healthypeople.gov, 2014). Wei, Findley, and Sambamoorthi (2006) argue that oftentimes women with disabilities experience missed opportunities for use of clinical preventive care, because of multiple and complex medical needs that compete for attention from physicians. Other issues related to the disability itself often trump preventative care services and unrelated disorders are less likely to be treated. Wei et al., (2006) explain, the lack of cancer screening among individuals with disabilities is quite common, and results in unmet health needs.

The lack of awareness around preventative health care needs for individuals with disabilities was quite prevalent within the literature. Oftentimes, women with disabilities have incomplete breast cancer knowledge, especially those with lower income, education, and who are from a minority background (Berman, Cumberland, Booth, Britt, Stern, Zazove & Bastani, 2013). According to Rimmer and Rowland (2008) limited access to health care and health care follow-up among individuals with disabilities, is exacerbated from a lack of health promotion practices that provide health education and awareness.

The World Health Organization has documented a lack of health promotion efforts that specifically target individuals with disabilities, in addressing their unmet health needs. According to the World Health Organization (2014) “Health promotion and prevention activities seldom target people with disabilities. For example women with disabilities receive less screening for breast and cervical cancer than women without disabilities”. Greenwood, Wang,

Bowen, and Wilkinson argue (2013), “Evidence-based health education and health promotion interventions are important tools for reducing health disparities” (p.1).

Nutbeam (1998) describes health promotion as a process or activity with a clear beginning and end. It is something that is done with people rather to people, in an effort produce a particular health related outcome (Nutbeam, 1998). Health promotion involves individuals and groups in taking action and exerting control over determinants of health, through certain health behaviors (Nutbeam, 1998). Nutbeam (1998) argues that a change in the health of the individual or group as the result of an intervention, is considered to be a health outcome. A health promotion outcome is considered to be an immediate result of the planned health promotion activity (Nutbeam, 1998). Valued outcomes of health promotion include empowerment of communities and individuals, through behavioral actions that support healthy lifestyles and create supportive health environments (Nutbeam, 1998). Examples of health promotion outcomes are improved health knowledge and motivation concerning healthier ways of life (Nutbeam, 1998).

Rimmer and Rowland (2008) argue that health promotion efforts targeting individuals with disabilities may have a substantial impact on improving lifestyle, behaviors, increasing quality of life, and reducing medical costs. In general, health promotion programs for persons with disabilities should reduce secondary conditions, improve functional health, and eliminate environmental barriers to participation within the community (Rimmer, 2008). In terms of content there is a need for health promotion materials to be relevant for individuals with: physical, cognitive, sensory, and learning disabilities (Rimmer, 2011). Creating health promotion materials in accessible formats that are relevant to various types of disabilities, will enhance health promotion outcomes for this portion of the population (Rimmer, 2011).

Including persons with disabilities in the creation or design of health promotion materials and programs, may improve health promotion intervention outcomes for these individuals (Balcazar, 1998). Including persons with disabilities in the process of creating or designing a health promotion intervention is known as Participatory Action Research (PAR) (Balcazar, 1998). PAR is a distinct approach to research that aims to generate knowledge both quantitatively and qualitatively through research methods such as: participant observation, personal interviews, focus groups, and participatory needs assessment surveys (Balcazar, 1998).

Balcazar's (1998) study found the following: PAR acknowledges that participants have knowledge and expertise to share with trained researchers including their opinions about how the research should be undertaken. An important implication is that the research process can be both controlled by both the trained researcher and participants, who in-effect become co researchers (p.5).

The practice of utilizing PAR in creating health promotion interventions is quite common, especially within in the disability field. Faridi, Grunbaum, Gray, Franks, and Simoes, (2007) created a step by step process for community members, universities, academic researchers, and public health officials to utilize PAR in developing effective health promotion strategies. One of the criticisms of PAR is that a standardized way to measure the quality of research or effectiveness intervention themselves does not exist (Faridi, Grunbaum, Gray, Franks, & Simoes, 2007).

Health promotion programs for people with disabilities are still in the early stages of development (Ravesloot, Seekins, & White, 2005). Very little research exists on the effectiveness of health promotion interventions targeting women with disabilities, especially

those that focus specifically on increasing mammography utilization. The purpose of this thesis was to examine peer-reviewed research that examines health promotion interventions as a solution to increasing mammography utilization and awareness among women with disabilities. The aim of this thesis was to systematically review and assess peer-reviewed literature that has evaluated health promotion intervention programs targeting women disabilities, with an aim of increasing mammography utilization and awareness. The protocol for conducting this systematic review is described in the methods section.

Chapter 2

Methods

Systematic reviews were developed as a tool used within the evidence-based movement in medicine to answer very specific clinical questions, and apply the most informed and best evidence in making decisions for patients (Paynter, 2009). Systematic reviews are commonly conducted by healthcare practitioners and policy makers who aim to synthesize the best available evidence, identified by combing through relevant literature to answer questions of effectiveness. (Forbes, 2003). When healthcare providers, policy makers, and consumers are constantly bombarded with health care information, systematic reviews help manage information by synthesizing valid data and effects of an intervention (Forbes, 2003). Forbes (2003) argues that evidence-based practice within the behavioral and social sciences helps inform the decision making process by using the most relevant and up-to-date research, indicating which practices work best in a given situation. Dijkers and the Task Force on Systematic Reviews and Guidelines (2009) explain that although a shared definition for a systematic review does not exist, although systematic reviews generally follow the same steps.

White and Schmidt (2005) describe a five step protocol for conducting a systematic literature review, these steps are:

- Frame the question and choose appropriate methods.
- Identify relevant work.
- Extract relevant data on outcomes and quality.
- Summarize the evidence.
- Interpret the evidence.

Frame the Question and Choose Appropriate Methods

The first step in conducting a systematic review is to frame the research question (White & Schmidt, 2005). The research question determines the focus and aim of the systematic review, and should be a focused question that identifies effectiveness of an interventions (s) (Forbes, 2003). When developing the research question, there are three major components that must be included within the question which are: participants, intervention, and outcome. It is also important to include sub-questions as secondary aims that will result in a series of precise research questions guiding the review (Forbes, 2003).

For this review it was imperative to design a research question and sub-questions that would create a synthesis of what is known on the topic of health promotion interventions that specifically aim to increase mammography utilization among with disabilities. The questions were to provide a foundation of evidence-based knowledge pertaining to this topic, and examine the validity of what is found within the literature. The following research question and sub-questions guided this review.

Question:

What are the most effective health promotion interventions for mammography screening and awareness, targeting women with disabilities?

Sub-questions:

1. How effective are current health promotion intervention programs increasing mammography utilization and or awareness among disabled women?
2. How many health promotion interventions have been evaluated?

3. How reliable is the level of evidence for each intervention?
4. Do interventions focus on a specific type of disability more than others?
5. How many interventions incorporate PAR?

Identify Relevant Work

Identifying relevant work for a systematic review includes: a comprehensive database search, retrieval of relevant reports, and decisions pertaining to which studies should be included in the review. This is also referred to as the inclusion and exclusion criteria (White & Schmidt, 2005).

Inclusion and exclusion criteria. The inclusion and exclusion criteria are closely linked with the research question and should be established early on in the development stage, so it may serve as a checklist for which studies to include and exclude (White & Schmidt, 2005). Typically two types of inclusion criteria are used in a systematic literature review (Treadwell, Singh, Talati, McPheeters, & Reston, 2012). The first type pertains to publication characteristics such as: full article publications and not just abstracts, peer reviewed publications, the year of publication (to ensure the most up to date information is used), and English language publications (Treadwell et al., 2012). Also, the exclusion of duplicate publications may take place unless the duplicate studies contain unique outcome data (Treadwell et al., 2012). The second type of inclusion criteria pertains to study design, study conduct and reporting, and study relevance to key questions (Treadwell et al., 2012).

Inclusion criteria for this review addressed publication characteristics, study design characteristics, and population characteristics. If an article failed to meet all of the pre-specified

inclusion criteria, then it was excluded from the review. The initial inclusion/exclusion criteria at the beginning of the review included the following:

- All research articles must be peer-reviewed.
- All research articles must be published between the years 2000-2014.
- All health promotion interventions must be conducted within the United States.
- Each health promotion intervention must have a stated beginning and end.
- The population studied must only consist of adult women with any cognitive and or physical disability.
- The health promotion intervention must have the aim of increasing mammography utilization and awareness only.
- The article had to evaluate the intervention itself and report measured outcomes.

Database search and retrieval of relevant reports. I began searching for relevant articles within peer-reviewed academic journals that seemed to focus on health promotion, disability, or both. While searching for relevant articles, I would begin by assessing both the title and abstract. Depending on what was found, I would then decide whether or not to read beyond the abstract. The search was completed with the use of these primary key search terms: mammography, disability, and health promotion. Search terms that were used in addition to the primary search terms were: health education, preventive screening services, evidence-based, and intervention assessment. Primary search engines used in this search were: PubMed, Google Scholar, Web of Science, Science Direct, and Ebscohost. Primary journals used in this search were: *The American Journal of Health Promotion*, *Journal of Education and Health Promotion*, *Health Promotion International*, and *Disability and Health Journal*. The majority of literature found within this search focused on barriers to mammography utilization among women with

disabilities. Also, the majority of documented health promotion interventions lacked a mammography utilization component.

At the onset of the article search, I was able to find three peer reviewed articles that fit within initial inclusion/exclusion criteria. As a result of finding only three articles that fit within established inclusion criteria, the inclusion criteria was expanded. Four alterations were made to expand the search in hopes of finding more articles that fit within the inclusion/exclusion criteria:

- All research articles must be published between the years 1995-2014.
- All health promotion interventions must be conducted within an English speaking nation.
- The population studied may partially consist of adult women with any cognitive and or physical disability.
- The health promotion intervention must have at least one component that aims to increase mammography utilization and awareness.

I expanded inclusion criteria to include articles in all English speaking countries and include research between years 1995-2014. I also decided to include research that may also contain a male population within the study, although I would only focus on the female population. The final alteration made was to include research that contained a mammography utilization component, rather than only including studies who solely focused on mammography utilization as an objective. The new search strategy was similar in terms of process however, I also included the names of other English speaking countries, which led me to European health journals and articles. Expanding the inclusion criteria resulted in a sample of thirteen articles that seemed to fit within overall inclusion/exclusion criteria. The research question and sub-questions acted as a guide in determining whether or not to exclude any articles.

Table 1. Modified inclusion/exclusion for this review. Below is a modified list of inclusion and exclusion criteria that guided this review.

Include	Exclude
<p>Literature</p> <ul style="list-style-type: none"> • From 1995-2014 • That is peer-reviewed • From all English speaking countries • That examines health promotion interventions with a stated beginning and end point • Whose target population consists of adult women with a disability (even if men are included in another aspect of the study) • Evaluates a health promotion intervention and reports measured outcomes (on at least one component that aims to increase mammography utilization and or awareness) 	<p>Literature that</p> <ul style="list-style-type: none"> • Is not peer-reviewed • That does not describe a health promotion intervention with a stated beginning and end. • Do not contain a health promotion intervention component that aims to increase mammography utilization and/or awareness in any capacity • Do not evaluate the intervention itself and or report measured outcomes • Is a duplicate studies unless reported outcomes reveal new information

Excluded studies. A total of five articles were excluded from this review. Articles were excluded from the sample if they did not meet all inclusion/exclusion criteria. The first two articles that were excluded were duplicate studies that were found during the initial search with the first set of inclusion/exclusion criteria. I choose to include the primary study published in 2010, because it focused on effectiveness of the health promotion intervention itself and included

documented outcomes of the intervention. The other three articles were not duplicate studies and were excluded because they did not fit within at least one or more of the inclusion/exclusion criteria previously described.

The first duplicate study that was excluded is titled “Using Intervention Mapping to Promote the Receipt of Clinical Preventive Services Among Women with Physical Disabilities” (Suzuki, Peterson, Weatherby, Buckley, Walsh, Kailes, & Krahn, 2012). I chose to exclude this article because the aim of the study was to describe how the health promotion intervention was developed using intervention mapping, and the study outcome did not offer new information regarding the effectiveness of the health promotion intervention itself. The second duplicate study that was excluded is titled “Multi-Level Barriers to Obtaining Mammograms for Women with Mobility Limitations: Post Workshop Evaluation” (Suzuki, Krahn, Small, & Peterson-Besse, 2013). I chose to exclude this article because the aim of the study was to assess barriers and facilitators in mammography use, once the health promotion intervention took place. The outcome data focused on barriers to mammography utilization, rather than effectiveness of the health promotion intervention itself.

The third study I chose to exclude is titled, “Cancer Prevention and Health Promotion for People with Intellectual Disabilities: An Exploratory Study of Staff Knowledge” (Hanna, Taggart, & Cousins, 2011). The study examined and measured staff knowledge about cancer prevention as an intervention, within a managed care setting for individuals with an intellectual disability. This article was excluded from the review because the intervention lacked a clear beginning or end, which is one of the inclusion/exclusion criteria previously stated. The fourth study that was excluded is titled, “Disability and Preventive Cancer Screening: Results from 2001 California Health Interview Survey” (Ramirez, Farmer, Grant, & Papachristou, 2005). This

article was excluded because it aimed to evaluate general cancer screening compliance among both men and women with disabilities in California. Screening compliance was not related to a health promotion intervention with a clearly stated beginning and end point. The fifth and final article that was excluded is titled, “Breast Awareness within an Intellectual Disability Setting” (Kirby & Hagarty, 2010). This article aimed to analyze breast cancer knowledge among staff, and how it related to breast awareness among individuals with an intellectual disability within a managed care setting. Again, this article also lacked a health promotion intervention activity with a clear beginning or end.

Extract Relevant Data on Outcomes and Quality

Step three of conducting a systematic literature review is to extract relevant data on outcomes, and assess the methodological rigor and validity of what is found (White & Schmidt, 2005). Braverman and Arnold (2008) argue that methodological rigor consists of particular elements that assist in determining how confident one may be, in drawing conclusions from the results of what is being evaluated. Methodological decisions establish the nature of the data, how it is collected, analyzed, interpreted, and its impact on forms of bias (systematic error) (Braverman & Arnold 2008). Several measures rather than just one, may eliminate measurement bias and increase confidence on what has been identified and assessed (Braverman & Arnold 2008). Methodological rigor is directly related to the general consensus of which approaches are strongest, and result in a higher level of confidence in what was found (Braverman & Arnold 2008).

For this review quality and validity have been examined in three separate ways. The first is a matrix tool that provides a framework for cross-comparison. The second is a quality

assessment tool with a scoring system that examines validity, and the third is a level of evidence pyramid tool categorizes each article based on research quality.

Matrix tool. The matrix tool was the first step in extracting relevant data. The matrix was a spreadsheet that allowed for a comparative analysis of the entire sample through the systematic extraction of data. The objective of creating the matrix tool was to be able to answer the research question and sub-questions solely based on what was found within the literature sample. The matrix guided the data extraction process for every article in this review, and served as the framework for summarizing and synthesizing all relevant data.

The matrix was designed with the following categories:

- Author reference, year, and country of origin
- Target population
- Age range of participants
- Sample size (post attrition)
- The type of health promotion intervention
- Intervention parameter/length
- Qualitative or Quantitative Measures
- Outcomes
- Did the intervention increase mammography utilization?
- Quality assessment score (in relation to quality assessment tool)
- Research design and level (in relation to level of evidence pyramid)
- Whether Participatory Action Research (PAR) was mentioned

The first five categories provide information on: article reference, country of origin, disability type within the target population, age range of sample participants, sample size post attrition, and information on the type of health promotion intervention being evaluated. Sample size post attrition refers only to the portion of the sample who fully participated in the study, and does not include those individuals who were merely eligible to participate. Including the sample size post attrition was done so that intervention outcomes were only related to the population who completed the study. Information on the type of health promotion intervention revealed how varied health promotion interventions may be in terms of content, activity, and length (see Appendix A for a table showing this portion of the matrix).

The sixth and seventh categories examine the intervention parameter and length, providing information on how effectiveness was measured; qualitatively, quantitatively, or both. The eighth and ninth categories provide information on outcomes, and whether or not the intervention was successful in actually increasing mammography utilization among the population (see Appendix B for a table showing this portion of the matrix). Two factors were examined within the success category, and the first was whether or not the health promotion intervention resulted in the actual receipt of a mammography screening by study participants. The second factor examined was whether or not the health promotion intervention resulted in an increase of awareness or an increase in knowledge, pertaining to mammography screening.

The tenth category provides a quality assessment score (in relation to quality assessment tool) for each article. The quality assessment score reveals how proficiently evidence has been documented within the article. The quality assessment tool consists of a rating process, described in the quality assessment section. The eleventh category provides information pertaining to research design and level (in relation to level of evidence pyramid), described in the level of

evidence section. This category examines how reliable the evidence in the article is, based on the type of study design used. The twelfth category reveals information about whether or not participatory action research was mentioned within the study, in any capacity (see Appendix C for a table showing this portion of the matrix).

Participatory action research. Participatory action research (PAR) is a public health approach that aims to improve health and reduce health inequities by involving the individuals, who in turn take actions to improve their own health (Baum, MacDougall & Smith, 2006). Baum et al., (2006) argues that PAR is based on reflection, data collection, action, and as a methodology it allows researchers to work in partnership within the communities being examined. The process of PAR should be empowering for participants, and should result in the participants having more control over their lives (Baum et. al, 2006).

Within a health promotion context, the principles of PAR have formed empowerment evaluation which argues that the evaluation of health promotion should include the individuals whose health is being promoted (Baum et. al, 2006). Empowerment evaluation strives to be a more democratic process by building capacity, encouraging self-determination, and making evaluation less expert driven (Baum et. al, 2006). At the heart of PAR is self-reflective inquiry that both researchers and participants take, so they can understand and improve upon practices or situations (Baum et. al, 2006). PAR within the context of this review refers to whether or not the health promotion intervention includes the target population in any part of the process, from development to evaluation.

Quality assessment. The second indicator was to assess the validity and methodological rigor of each article by assigning a rating based on the characteristics below. The assessment tool used in this review is a slight adaptation of assessment criteria developed by Naaldenberg,

Kuijken, van Dooren, and van Schrojenstein Lantman de Valk (2013). Naaldenberg et al., (2013) initially used this assessment in a structured review that examined health promotion interventions among adults with intellectual disabilities. Each article was reviewed carefully and systematically, guided by eight quality assessment criteria components, and then rated depending on how proficient the information in each article was. All papers were assessed by myself and then approved independently by my faculty advisor. The following questions were used in the assessment of all of the articles.

Quality assessment was based on the following criteria:

1. Is there a clear description of aim(s) and research question(s)?
2. Is there a clear description and discussion of rationale for sample size chosen?
3. Is there a description and discussion of research population?
4. Is there a description and discussion of attrition rate?
5. Is there a description and discussion of measurements used?
6. Is there a discussion of study limitations?
7. Is there a description of intervention development?
8. Is there a description of intervention content?

The highest score possible for each paper is 16 points. Two points per criteria were given if the information was provided with a clear description. One point was given if partial or incomplete information was provided, and a description or explanation was lacking. A half point (.5) was added if the content was considered to have a proportion of both marginal and

somewhat clearly stated information. Lastly, no points were assigned to each component if the article lacked any information, pertaining to the question asked.

Level of Evidence. The level of evidence pyramid was used to assess how reliable the findings are, based on the methodological rigor and reliability of each study. Paynter (2009) explains that a hierarchy of evidence pyramid displays a ranking of evidence from top to bottom, based on how rigorous the research is. Within the level of evidence pyramid, one can visualize how reliable a particular research-based claim is, based on categorization within the pyramid. Research that is categorized within the top of the pyramid represents the most reliable evidence, and research located within the bottom of the pyramid represents the least reliable evidence. The level of evidence pyramid serves as a tool, intended to assist in gauging which evidence professional decisions should be based upon (Paynter, 2009). The evidence pyramid used in this review and described by Paynter (2009) has four levels categorized by the type of study design described in each article.

Level I. A level I category includes research that must contain a manual or practice guideline (Paynter, 2009). Paynter (2009) describes a practice guideline or manual as a best practice framework which allows for clinical decisions to be made, and may also be used as a benchmark against the evaluation of clinical practice. Research within this category requires the rigorous use of systematic identification and appraisal (Paynter, 2009).

Level II. A level II category includes research that must contain a systematic review or meta-analysis (Paynter, 2009). Paynter (2009) describes a systematic review as something that retrieves, appraises, and summarizes all of the available evidence on a specific question, and then attempts to reconcile and interpret it. Systematic reviews are undertaken to provide information

across a wide range of settings, empirical methods, and examine the extent to which empirical evidence supports or refutes a hypothesis (Paynter, 2009). A meta-analysis is research that combines the results of a number of studies, and then analyzes the results statistically as a single data set (Paynter, 2009).

Level III. A level III category includes research that must contain a randomized control trial (RCT) or have quantitative research methods. The Cochrane Collaboration (2014) describes an RTC as a study design that has one or more comparison groups, that are (control intervention or no intervention) randomly allocated to participants and compared. In most trials one intervention is assigned to each individual, but sometimes assignment is to defined groups of individuals (Cochrane Collaboration, 2014). This category also includes cluster randomized control trials which are similar to an RTC, except clusters or groups of individuals are randomized and compared rather than a single individual (Cochrane Collaboration, 2014). Quantitative studies include research with statistical inference to draw conclusions about the population (Paynter, 2009).

Level IV. A level IV category contains qualitative studies or a clinical experience (Paynter, 2009). Qualitative studies can be understood as non-numerical data or analysis collected by methods of in-depth interviews, focus groups, and participant observations in the form of a narrative (grouped together by themes or concepts as the analytical device). (Dixon, Fitzpatrick, Roberts, 2008). Paynter (2009) describes qualitative research as the detailed descriptions and particularized interpretations of people through social, cultural, and linguistic interpretations of events. A clinical experience is a type of evidence that has not been subjected to rigorous study, and is not considered an evidence-based practice when relied on independently (Paynter, 2009).

Chapter 3

Results

Summarize the Evidence

Findings. Eight articles were systematically reviewed that fit within inclusion and exclusion criteria previously described in the methods section. Of the eight articles, disability was classified in three ways: mobility impairment (MI), intellectual disability (ID), and learning disability (LD). One article focused on individuals with MI, four articles focused on individuals with LD, and three articles focused on individuals with ID. The research articles included in this review were published between years 1998-2013. Four articles were from the United Kingdom, two articles were from the United States, one article was from Australia, and one article was from Ireland.

Out of eight articles, five were classified within the level III category because the study either contained a RCT, or provided quantitative measures. The other three articles were classified within the level IV category because measured outcomes were qualitative. There were no studies found that fit within a Level I or Level II category within this sample. This means that the most reliable evidence found in the literature is categorized in either a level III, or level IV category. Two out of eight articles reported an increase in mammography utilization as the result of the health promotion intervention.

Article Description. The following analysis is a summary of the eight articles within this sample, each categorized by their respective level of evidence categories described by Paynter (2009) in the previous section. The summary includes details about: the intervention, sampling, evaluation method/ tools used, and findings.

Level I. There are no studies in this sample that were categorized within level I criteria.

Level II. There are no studies in this sample that were categorized within level II criteria.

Level III. Peterson, Suzuki, Walsh, Buckley, and Krahn (2012) described a randomized control trial (RTC) of a participatory workshop called, Promoting Access to Health Services (PATHS). The aim of the study was to evaluate the effectiveness of PATHS, as a cancer screening health promotion intervention targeting women with mobility impairments. PATHS was a 90-120 minute participatory-small group workshop with a mean of about four participants per workshop, and six-months of structured telephone support (2.3 calls completed with each participant) (Peterson et al., 2012). The educational component of the workshop included information on: breast and cervical cancers, susceptibility to those conditions, screening benefits, procedures, and recommendations about overcoming barriers for screening (communicating with physicians, setting goals, and initiating change) (Peterson et al., 2012). Written materials consisted of an educational workbook, informational brochures, and a copy of the training presentation (Peterson et al., 2012). To accommodate women with low literacy rates, it was mentioned that written materials also included pictures that paralleled verbal messages (Peterson et al., 2012).

The women in the study were between 35-64 years old, with mobility impairments (Peterson et al., 2012). The majority of the woman were not employed, and reported an annual income of <\$10,000 (Peterson et al., 2012). Recruitment was completed through the following channels: medicaid managed care organization, durable medical equipment vendor, and state-funded community based clinics within Oregon (Peterson et al., 2012). To be eligible for the study, the women had to self-report that they were not up to date with Pap testing and/or

mammography, had to be English speakers, and had to have health insurance (Peterson et al., 2012). Eligible women were enrolled and randomly assigned to either the intervention or control group (Peterson et al., 2012). All measures were self-reported through a paper-and-pencil survey that was statistically analyzed (Peterson et al., (2012) Chi-square tests examined the difference between control and intervention groups before and after each screening (Peterson et al., 2012). For mammography post-test screening, there was no significant group effect reported for mammography screening (Peterson et al., 2012).

In comparison with all of the articles within this sample, this article had the highest quality assessment score of 14.5/16. It was mentioned that the workshop and structured telephone support was led by women with mobility impairments, however It was not mentioned whether or not women with mobility impairments played a role in the development of the intervention. The main outcome of PATHS was, it did not promote mammography testing, but did promote Pap screening among the sample (Peterson et al., 2012).

Lennox, Bain, Rey-Conde, Purdie, Bush, and Pandeya (2007) describe a health promotion intervention called, the Comprehensive Health Assessment Programme (CHAP). CHAP was a primary care-based intervention within a managed care setting in Queensland, Australia and was meant to address preventive health care needs for adults with intellectual disabilities (ID) (Lennox et al., 2007). The CHAP intervention was a 21 -page health information booklet divided into two parts, and was designed to be used by the individual with ID, their caregiver, and their general practitioner (Lennox et al., 2007). The first part covers medical history, which is completed by caregiver and the second part was to be completed by general practitioner. Once the general practitioner filled out his/her portion pertaining to the individual's health, the information was then used in conjunction with the caregiver to create a

health action plan (Lennox et al., 2007). The CHAP study lasted for one year, and follow up lasted for one year post intervention (Lennox et al., 2007).

The sample consisted of 707 male and female adults who had ID and lived in 24-hour residential care homes (Lennox et al., 2007). Recruitment was completed with the assistance of residential staff and guardians who were sent an informational booklet, consent form, and invitation to participate (Lennox et al., 2007). For this review I only examined outcomes within the female population. The proportion of female participants was 200 women, out of 453 adults (Lennox et al., 2007). Within this proportion, there were 93 female participants in the intervention group and 107 female participants in the control group (Lennox et al., 2007). The study design was a cluster randomized control trial, and the sample group was divided into 34 clusters (17 pairs) (Lennox et al., 2007).

The results revealed slightly higher rates of mammography utilization at 14.6% among the intervention group, compared to 4.1% in the control group. (Lennox et al., 2007). Lennox et al., (2007) also reported whether or not the CHAP tool was mentioned in relation to specific health needs within the general practitioner's notes. Within these notes, the rate at which mammography was mentioned along with the CHAP tool was 13.9%. The rate at which mammography was mentioned independently of the CHAP tool within the notes was 15.4%.

The findings of this study apply to individuals living within managed care settings and the author stated that this was the first published RTC intervention study, among adults with ID (Lennox et al., 2007). This article received a quality assessment score of 11.5/16 and there was no mention of PAR within the article. Overall this article had the highest quality assessment score among the articles that increased mammography utilization.

Greenwood, Wang, Bowen, and Wilkinson (2013) describe the evaluation of a health education DVD-based intervention that aimed to educate women with ID about mammography preparedness and utilization. The DVD takes the viewer through the process of a mammogram from start to finish, and is in a concrete story format (Greenwood et al., 2013). The story begins in the doctor's office when with the doctor recommends the actress (who actually has a form of ID) be referred for a mammogram, while explaining the process and purpose of the mammography (Greenwood et al., 2013). The actress navigates through all of the steps of the process: arriving at the clinic, asking questions, putting on the hospital gown etc... Then the mammography tech demonstrates the use of the mammography machine while ensuring the actress' comfort (Greenwood et al., 2013). Greenwood et al., (2013) explains, the actress is meant to be a positive role model who is relatable, and the DVD concludes with the actress back in the doctor's office, reviewing her results.

Women aged 37 and above were included in this study and recruited through two different strategies (Greenwood et al., 2013). The authors claimed to have a diverse population, however the article lacked in providing demographic information and only included age, residence type, and whether or not the individual had a previous mammogram (Greenwood et al., 2013). The population was in a heavily mandated health insurance coverage area, and 92% of women within the study had a prior mammogram (Greenwood et al., 2013).

The sample consisted of 46 women who watched the DVD in a group, and were then given pretests and posttests (Greenwood et al., 2013). Outcomes were measured with the use of a tool called the mammography preparedness measure (MPM), which was developed and validated by the research group (Greenwood et al., 2013). The tool was created to measure "readiness" and or concrete knowledge of mammography itself, as well as the procedure mammography

screening entails (Greenwood et al., 2013). The instrument was administered verbally and used a story format to test the participant, followed by the completion of a Likert-scale survey by the participant (Greenwood et al., 2013). Following the post-DVD survey, results indicate an increase in correct answers pertaining to the mammography procedure. The Pre-DVD score was 3.8/5 and the post-DVD score was 4.2/5. The question that had the biggest increase post-DVD was: “When I have my mammogram, how long will I be in the machine?” (Greenwood et al., 2013).

The authors recommend the DVD as a low-cost and easy to distribute form of health education, however one of the limitations of this study was a lack of follow-up with participants post-study completion (Greenwood et al., 2013). It is unknown how many participants actually received a mammogram as the result of the DVD itself. The authors recommended that a more comprehensive trial such as an RTC be initiated for a closer evaluation of effectiveness, resulting in mammography utilization. This study had a quality assessment score of 12.5/16 and did mention PAR. Greenwood et al., (2013) argued the intervention demonstrated demand and acceptability among women with ID, for a media-based health education DVD that increased mammography awareness.

Lalor and Redmond (2009) describe the evaluation of an extensive national media campaign, inviting women to register for mammography screening in Ireland. The program called, *BreastCheck* invited all eligible women within a national database between the ages of 50-64 to be screened (Lalor & Redmond, 2009). Lalor and Redmond (2009) directly attributed mammography utilization and clinical breast exams within the sample group to the health promotion intervention *BreastCheck*. However, the article lacked any detailed information about

the health promotion *BreastCheck* media campaign itself. The media campaign lasted seven years from 2000-2007 (Lalor & Redmond, 2009).

Outcomes within this study were measured with a survey questionnaire that determined whether or not the national health media campaign and database had increased mammography utilization among the sample population. The survey was completed by post-menopausal women with learning disabilities (or by their caregivers), living in long-term care between the ages of 50-64 years old (Lalor & Redmond, 2009). Sample selection and survey completion was facilitated by caregivers, nursing staff, and social care workers. The study sample consisted of 90 women who completed the survey, resulting in a response rate of 69.7% (Lalor & Redmond, 2009).

Lalor and Redmond (2009) reported that out of the 90 respondents, only 85.6% of women had received an invitation from the *BreastCheck* campaign. Lalor and Redmond (2009) suggested there was a 14% discretion in the receipt of invitations because the national database was not comprehensive enough, or that a glitch may have existed within the database. Two thirds (67%) of the sample, reported completing mammography screening because of Breast Check (Lalor & Redmond, 2009). Within the 90 women surveyed, 60 successfully completed mammography and 24 received a clinical breast examination (Lalor and Redmond 2009). Lalor and Redmond (2009) claimed that the *BreastCheck* campaign seemed to encourage awareness and utilization of mammography, oftentimes with the help of caregivers. Lalor and Redmond (2009) also mentioned the database required self-registration and emphasized the importance of service providers to take on the role of registration for individuals who were unable to register independently. This article received a quality assessment score of 8.5/16 and there was no mention of PAR.

Biswas, Whalley, Foster, Friedman, and Deacon (2005) describes the evaluation of an intervention among women with learning disabilities in the United Kingdom. This intervention was a health education intervention administered by nurses about the process and benefits of breast and cervical screening (Biswas et al., 2005). Learning disability nurses in Burnley and Rossendale (BPR) Primary Care Trust, developed a tool kit that consisted of a health education pack and care pathway (Biswas et al., 2005). The care pathway was a tool designed to help nurses work with various levels of understanding and ability, and also guided ethical issues of consent and best interest, while working with individuals with LD (Biswas, et al., 2005).

The sample was recruited through the use of a national database called (COMWISE) which was contained a list of all women with LD who had come into contact with the NHS Learning Disability Service (Biswas et al., 2005). The nurses attempted to record the names of eligible women within the database and make contact with them in order to identify whether or not they were due for a screening (Biswas et al., 2005). For the women who had not been screened, the intervention relied heavily on nurses through administering one to one counseling with women with LD's (Biswas et al., 2005). The final sample consisted of 48 women between 54-64 years old (Biswas et al., 2005).

Biswas et al., (2005) explained that measured outcomes were examined by comparing the proportion of women who were current with mammography and pap screening, with those who were not. Of the eligible 48 women, 37 had undergone breast screening, however, these numbers were recorded in an audit prior to the one on one counseling and are not a direct result of the intervention (Biswas, et al., 2005). This article received a quality assessment score of a 9.5/16 and there was no mention of PAR within the study. This article lacked detailed information on the materials used by the nurses for one to one counseling.

Level IV. Cowie and Fletcher (1998) described a health promotion intervention created for adults with LD in a residential group setting in the United Kingdom. The aim of the intervention was to increase mammography screening & awareness among long-term residents, through the training of nurses at the facility (Cowie & Fletcher, 1998). Cowie and Fletcher (1998) explained, the intention of the intervention was to educate and teach all female service users (individuals who lived within the managed care setting) to be breast aware and to understand self-breast exams, but if this was not possible the nurses would step in and ensure that the women had access to breast screening procedures. It was unclear how many nurses completed the training and how many individuals were approached by the nurses.

According to Cowie and Fletcher (1998), the result of the intervention was successful and increased monthly checks and registration for mammography. Cowie and Fletcher (1998) claimed that 45% of female residents were receiving monthly checks post intervention, and this was likely to increase once more staff were trained. Cowie and Fletcher (1998) argued that the intervention was effective in increasing mammography utilization and awareness, however the article lacked any data that confirmed this number. The article received a quality assessment score of 5/16 and there was no mention of PAR.

Poynor (2003) described a descriptive case study of her own involvement in the design and piloting of the health promotion intervention, *Breast Screening at the Jarvis Centre* teaching pack. The teaching pack consisted of health related materials developed specifically for women with learning disabilities, suitable for individuals or groups (Poynor, 2003). The teaching pack contained drawings, pictures, and symbols that were specifically tailored for women with LD, in an effort to increase awareness around breast cancer and mammography utilization (Poynor, 2003).

Poyner (2003) mentioned collaboration with a group called Lambeth's People First, led by persons with learning disabilities in order to create an appropriate picture style with teaching materials. Also, a publication was referenced within the article by Lambeth's People First, which served as a guide for cancer awareness for people with learning disabilities in the teaching pack (Poyner (2003)). Poyner (2003) argued that the dual aims of creating the teaching pack were to not only create breast cancer awareness for the women with LD, but to also create awareness among nurses and caregivers that support them. Recognition of the critical role of caregivers led the author to try and ensure that the package would be useful in supporting women with LD (Poyner, 2003).

The sample within this article consisted of ten women who lived in residential care, independently, and in a group home. Poyner (2003) mentioned that the teaching pack was piloted among groups of women facilitated by a self-advocacy group and day service personnel. A list of qualitative responses from both women with ID, caregivers, and supporters were documented at the end of the article and seemed quite positive overall. Poyner (2003) explained that evaluation of the pack was facilitated by 30 out of 50 professionals who shared their views on the teaching pack, and said the material was positive and supportive. Among the feedback, self-reported changes in attitude and an increase in knowledge were mentioned by Poyner, however there is no evidence of actual behavior change (Poyner, 2003). This article received a quality assessment score of a 5/16 and did mention the use of PAR.

Gilbert, Wilkinson, and Crudgington (2007) described a project whose aim was to create a communication tool that enables individuals with ID to better understand cancer, and communicate their needs. Gilbert et al., (2007) emphasized the importance of empowering the individual through education and utilized something called, 'total communication technique'

which is an approach that assists with speech augmentation utilizing: signs, symbols, objects, pictures, photographs, facial expressions, and body language. The health promotion pack is divided into two parts called health promotion & cancer journey, along with three sections: how to use the pack, principles underpinning the total communication techniques approach, and tools related to expressing pain and symptom control (Gilbert et al., 2007). Gilbert et al., (2007) explained, there were 25 different symbols expressing pain and symptom control; 11 are designed for use with health promotion, and 14 are for support with the cancer journey. The authors also set up a website where individuals could download the pack for free (Gilbert et al., 2007). Breast awareness was only one of the cancer awareness components focused on in the teaching pack.

Evaluation of the teaching pack was completed by tracking the dissemination of materials, focus groups, a questionnaire, and follow-up interviews (Gilbert et al., 2007). The authors mentioned there were only 10 phone interview participants, with a 16% response rate (18 questionnaires) (Gilbert et al., 2007). The article included two brief qualitative comments from respondents and overall there was very little evidence for actual effectiveness of the teaching pack. Gilbert et al., (2007) argued that the tool had great potential in creating awareness for cancer related health needs of people with ID. This article had an assessment score of a 9.5/16 and did mention the use of PAR.

Comparative assessment. The following analysis is comparative assessment that combines the articles based on homogeneity. The only two articles that contained RTC study designs with the highest level of evidence within the sample, were from the United States and Australia. As previously described, RTCs are considered to be more reliable in terms of study design because of the use of random allocation, and the opportunity to compare control and

intervention groups (Peterson et al., (2012) level III, Among the two articles with the highest level of methodological rigor, only the article by Lennox et al., (2006), level III, was slightly effective in increasing mammography utilization.

Learning disability. Four out of eight articles in this sample, focused on health promotion interventions for women with a learning disability. (Biswas et al. , 2005, level IV, Cowie and Fletcher 1998, level III, Lalor and Redmond, 2009, level IV, Poynor 2003, level IV). Within this group, only one article described a health promotion intervention that resulted in an increase in mammography utilization, although the article lacks empirical evidence that supports this claim (Cowie and Fletcher, 1998, level IV). The importance of caregivers, support staff, family members, and nurses were well documented in these studies. Two of the articles described health promotion interventions that took place within residential managed care settings. (Cowie and Fletcher 1998, level III, Poynor 2003, level IV).

Oftentimes mammography awareness and preparedness may only be possible through the training of staff and caregivers. The four articles within the LD category mention necessary involvement from either nurses or caregivers, and link their involvement with the success of the intervention (Biswas et al., 2005, level IV, Cowie and Fletcher 1998, level III, Lalor and Redmond, 2009, level IV, Poynor, 20013, level IV). For women who rely on caregivers and or family members for daily care, it is imperative that caregivers are aware of the need for preventative screening. Biswas et al., (2005),Cowie and Fletcher (1998), Lalor and Redmond (2009) all mention a centralized database of registered individuals that assists with keeping track of who has been screened, and who has not. Within managed care settings, screening audits may be an important component of successful health promotion interventions, as described by Biswas et al., (2005).

Intellectual disability. Three articles within this sample focus on women with ID (Greenwood et al. , 2013, level III, Gilbert et al. , 2006, level IV, Lennox et al. , 2007, level III). In the article by Lennox et al., (2007), level III there is empirical evidence that the health promotion intervention known as CHAP, slightly increases mammography utilization among adult women with ID. The CHAP intervention was unique within the sample because it was designed to improve overall health needs for male and female adults with IDs within a managed care setting, and incorporated the general practitioner, caregiver, and the individual within the intervention.

The article by Gilbert et al., (2007) explained that the ‘Living with cancer’ communication pack was developed to empower individuals with ID by allowing them to understand cancer as a whole, and at the same time be able to communicate their needs. (Gilbert et al., 2007). Greenwood et al., (2013), level III and Gilbert et al., (2007), level IV do not claim to increase mammography utilization, but propose their health promotion materials increase knowledge and awareness of mammography and related practices.

Mobility Impairment. One article within this sample targeted women with mobility impairments (Peterson et al., 2012, level III). The PATHS intervention was the only study that focused on women with mobility impairments, and was not successful in increasing mammography utilization (Peterson et al., 2012 level III). Peterson et al. , (2012) mentioned that the failure to increase mammography utilization as the result of PATHS may be in lieu of additional barriers associated with the process of a mammogram, although there was an increase in PAP screening (Peterson et al. , 2012, level III).

The following articles did report an increase in mammography screening as a result of the health promotion interventions evaluated. The CHAP program empirically had slightly higher rates of mammography utilization, in comparison with the control group for women with ID in Australia (Lennox et al., 2007, level III). In the United Kingdom, Cowie and Fletcher (1998), level IV, reported an increase in both mammography utilization and awareness, however empirical evidence does not exist in support of this claim.

The following interventions did not claim to increase mammography screening and or awareness. The PATHS intervention failed to promote mammography screening, but was shown to promote Pap testing among women who had mobility impairments (Peterson et al., 2012, level III). Poynor (2003), level IV, claims the teaching material pack she piloted may have increased knowledge and awareness among women with LDs, however there was no evidence of actual behavior change. Gilbert et al., (2007) level IV, claims the ‘Living with cancer’ communication pack may provide individuals with ID a moderate increase in mammography knowledge however, the authors never followed up with participants and were unaware whether or not the DVD did actually increase mammography utilization (Greenwood et al., 2013, level III). Greenwood et al., (2013), level III and Poynor (2003), level IV claimed to increase mammography awareness only, and not mammography utilization through the use of their health promotion interventions.

Four articles within this sample, incorporated PAR within some capacity, however none correlated the use of PAR directly with an increase in mammography utilization. (Gilbert et al., 2007, Level IV, Greenwood et al., 2013, Level III, Poyner 2003, level IV, Peterson et al., 2010, level III). Greenwood et al., (2007), (level III) incorporated a woman with ID as the spokesperson in the health education DVD, and consulted with her directly about the contents of

the script used in the DVD. Greenwood et al., (2007) level III, was the only article that incorporated PAR, and had empirical data in support of an increase in mammography awareness. People with ID were included in the development of the 'Living with cancer' communication pack (Gilbert et al., 2007, level IV). Gilbert et al., (2007) level IV, mentioned people with ID were included in two one- hour focus groups that took place over two weeks. The individuals who participated in the focus groups were also employees of the factory that made the packs (Gilbert et al., 2007, level IV).

Chapter 4

Discussion

The final step of conducting a systematic literature review is to interpret the evidence (White and Schmidt, 2005). This thesis systematically examined and evaluated a broad range of health promotion interventions that aimed to increase mammography utilization and awareness among women with disabilities. Rather than focus on barriers, it was imperative to evaluate and analyze the effectiveness of health promotion interventions as a solution in combatting this disparity. The research question and sub-questions chosen for this review allowed for a broad range of literature to be examined, in terms of health promotion intervention, disability type, and setting.

This review revealed that there is a high need for further research on this topic. Within the literature, very little evidence-based research was found supporting a most effective type of health promotion intervention. Even less research on this topic was found that contained a high level of methodological rigor. The sample size within this review consisted of only eight articles worldwide, and out this sample only three studies revealed some level of effectiveness, in terms of mammography utilization and or awareness. Only two articles within this study contained RCTs, and only one of these was slightly effective in increasing mammography utilization and awareness. The majority of the research found was qualitative in nature, which served as an informative and descriptive component to this review, however not reliable in terms of evidence.

The health promotion interventions within this review revealed that women who have mobility impairments, intellectual disabilities, or learning disabilities all have specific preferences and needs regarding the intervention format and length. What was found was that

effective health promotion interventions vary in formats, and must be tailored to meet the needs of the individual depending on type of disability and setting. Utilizing PAR in the development of health promotion intervention formats and supplementary materials was a common theme within the literature, and was mentioned 50% of the time.

Within a managed care setting individuals with disabilities seemed to have a distinct set of challenges, especially among individuals who relied more heavily on caregivers. Proficient training of nurses, guardians, caregivers, and general practitioners seemed to be a key component in an intervention's success, especially for women who are unable to consent to mammography screening. Focusing on a specific disability or type of health promotion would have made the review more comprehensive, however the literature needed for that type of review does not exist at this point.

Research that examines the effectiveness of health promotion interventions that specifically aim to increase mammography utilization among women with disabilities, is almost non-existent. Within the context of policy and evidence-decision making, there is a heightened need for more advanced research on this topic around the world. Health promotion intervention activities have the capacity to address mammography underutilization among women with disabilities, however first step is uncovering what type of health promotion is actually effective among various settings and disability type.

This issue is quite complex, so for future research and or possible next steps it may be beneficial to examine literature on effective health promotion interventions in general then apply principles and concepts on what is known to be effective. For example, examining successful health promotion interventions that have resulted in positive health outcomes and or behaviors,

for other chronic diseases. Since there is limited research on women with disabilities in general, it may also be beneficial to examine other groups of women who share similar characteristics or demographics such as: low income, low levels of education, non-English speakers, minority backgrounds, and those who don't have insurance. Since more literature exists on women who share these characteristics, there may be some elements that are transferable within a disability context.

Reducing and preventing breast cancer mortality among the most vulnerable populations, is a serious public health issue for any government. As a public health concern there is the need for public policy to address and support this issue. Public policy has the power to influence health behaviors and outcomes and is an extremely powerful and persuasive tool. When looking at the larger picture, health promotion as an intervention may be extremely useful in combatting this disparity. However, policies that would properly guide the health promotion intervention are needed and would need to be based on research and empirical evidence. Within the context of a national government whose resources are limited, decisions to invest on particular health interventions must always be based on valid research and evidence, including health promotion interventions, otherwise how would we know whether or not it's effective?

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Appendix A

Matrix Part 1

Reference (year) (country)	Target Population	Age Range	n (post attrition)	Type of Health Promotion Intervention
1. Petereson et al. , (2012) (USA)	Mobility Impairment	35-64	156	90 to 120-minute participatory small-group workshop. Also, activity workbook, informational brochures, and a copy of the training presentation
2. Cowie and Fletcher (1998) (UK)	Learning Disability	50-64	unclear	Policy designed to increase mammography screening & awareness among long-term service users in a residential group home through training of nurses at facility.
3. Poynor (2003) (UK)	Learning Disability	Never mentioned	10	The creation of a teaching pack called Be Breast Aware. Included pictures, symbols, and directions for learning about breast cancer & care
4. Biswas et al. , (2005) (UK)	Learning Disability	50-64	48	One to one counseling by a community learning disability team nurse using a "tool kit" with a health education pack
5. Lalor and Redmond (2009) (Ireland)	Learning Disability	50-64	90	Breast Check Health Promotion Campaign & Invitation to receive mammography
6. Lennox et al. , (2007) (Australia)	Intellectual Disability	19-73	200 women out of 453 adults. Intervention n=93, control n=107	Comprehensive Self Assessment Program (CHAP) 21 page health info. booklet. First part covers medical history (& completed by carer). Second part was completed by general practitioner and used with carer to create health action plan.
7. Greenwood et al. , (2013) (USA)	Intellectual Disability	37 and above	46	DVD based health education intervention (takes viewers from start to finish of mammography process)
8. Gilbert, Wilkinson, Crudgington (2006) (UK)	Intellectual Disability	Never mentioned	10	The 'Living with cancer' communication pack. Consisted of 2 parts & 3 sections. 'Health Promotion' & 'Cancer Journey'. Consisted of symbols which supported these topics

Appendix B

Matrix Part 2

Reference (year) (country)	Intervention Parameter/Length	Qualitative or Quantitative Measures	Outcomes
1. Petereson et al. , (2012) (USA)	Structured telephone support for 6 months-12 months	Quantitative. Self-reported survey/ Chi-square tested difference between groups for proportion receiving each screening & analysis of covariance tests used to test difference between groups for each theoretical mediator (controlling for pre-test mean)	No significant group effect was observed for mammography. PATHS intervention promotes PAP testing but not mammography
2. Cowie and Fletcher (1998) (UK)	Nurses completed 2 day comprehensive training course	Qualitative. Dissemination of knowledge from nurses/staff	learning disability at facility between ages 50-64 were registered for breast cancer screening. "To date, 45% of female service users are receiving monthly checks. The remaining women who are eligible
3. Poynor (2003) (UK)	Breast Awareness at the Jarvis Centre-Teaching Pack/Timeline wasn't given	Qualitative. Dissemination of knowledge from nurses/staff	Changes in attitudes and knowledge, however no evidence that there were behavior changes
4. Biswas et al. , (2005) (UK)	One to one interviews to encourage uptake of cervical screening. Took about a year to complete the entire project	Quantitative through use of an audit and comparison of proportions of women who were current and not current with mammography and pap screening	Of the eligible 48 women 37 had undergone breast screening "indicating that uptake was excellent and comparable to the national average (UK). However, the article explained these numbers were recorded in an audit prior to the one on one counseling and not a result of the intervention
5. Lalor and Redmond (2009) (Ireland)	Be Breast Aware Media Campaign 2000-2007	Quantitative. A questionnaire survey that consisted of 24 questions that collected data on mammography utilization and clinical breast exams among population	Two thirds (67%) of women surveyed reported completing mammography screening through Breast Check. 14% of women never received an invitation which reveals an inadequacy in Breast Check's database.
6. Lennox et al. , (2007) (Australia)	12 months/Follow up was for 1 year post intervention, outcomes extracted from clinical records	Quantitative. CHAP tool. Exit interviews were conducted but results weren't shown	16.5% of women in intervention group received breast exams compared to 8.8% in control. 14.6% of women in intervention received mammography compared red to 4.1% in control. CHAP
7. Greenwood et al. , (2013) (USA)	Study activities conducted over the course of two study visits: approximately 3 to 6 weeks apart	Both qual. & quan. /limited efficacy testing/evaluation of acceptability, demand, and limited efficacy through MPM tool (verbally administered Likert-scale questionnaire pre/post- tests)	Participants rated the statement "they had learned about mammograms from the DVD" a 4.4 out of 5
8. Gilbert, Wilkinson, Crudgington (2006) (UK)	Focus Groups (1 hour), Questionnaire (16% response rate), Follow-up telephone interviews,	Qualitative. Although there was a questionnaire component, there was no empirical evidence of this in the article itself. 2 Qualitative comments were shown	Author claims, Evaluation suggests the pack is an important tool supporting cancer communication among people with ID. Individual sections rated well, in relevance, usefulness, and accessibility

Appendix

Matrix Part 3

Reference (year) (country)	Did the intervention increase mammography utilization?	Assessment Score	Design & Level	PAR Mentioned?
1. Petereson et al. , (2012) (USA)	No	14.5	RTC/ III	Yes
2. Cowie and Fletcher (1998) (UK)	Yes	5	Descriptive case study/III	No
3. Poynor (2003) (UK)	No	7	Descriptive case study/IV	Yes
4. Biswas et al. , (2005) (UK)	No	9.5	Descriptive case study/level III	No
5. Lalor and Redmond (2009) (Ireland)	Yes	8.5	Exploratory descriptive study/IV	No
6. Lennox et al. , (2007) (Australia)	Yes. Slightly	11.5	RTC/ III	No
7. Greenwood et al. , (2013) (USA)	No, but DVD led to a moderate increase in mammography knowledge among women with ID	12.5	Descriptive feasibility case study/III	Yes
8. Gilbert, Wilkinson, Crudgington (2006) (UK)	No. Unknown whether or not the health education pack results in actively seeking mammography. However the tool can be used for communication purposes	10.5	Descriptive case study/IV	Yes