

BARRIERS TO BREAST CANCER SCREENING AMONG
WOMEN AGED 40 YEARS AND OLDER WHO HAVE PHYSICAL DISABILITIES

by

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(Under the Direction of Kevin DeWeaver)

ABSTRACT

Background

Breast cancer is a public health concern for all women, including women with disabilities. These women are as likely as women without disabilities to have ever received a mammogram; however, they are significantly less likely to have been screened within the recommended guidelines. Although the public health community has increased breast cancer awareness and encouraged women to adopt preventive practices, few programs exist that target women with disabilities.

Methods

The Centers for Disease Control and Prevention conducted a qualitative study to explore the barriers to breast cancer screening and treatment for women with physical disabilities. Focus groups were conducted in seven regions across the United States. Participants were assigned to one of three groups: Group A, women with physical disabilities who had never received a mammogram or had not received one within the recommended guidelines (>2 years); Group B, women with physical disabilities who had received a mammogram within the recommended guidelines (≤ 2 years); and Group C, women with physical disabilities who had survived breast

cancer. The primary research question was, “What are the barriers to breast cancer screening and treatment for women with physical disabilities?” Additional subquestions were asked to explore perceived risks for breast cancer, knowledge of mammography, interactions with the health care system, preventive behaviors, and environmental barriers to screening.

Results

Barriers fell into three categories: attitudinal, environmental, and system barriers. Frequently cited barriers included: perceived susceptibility, pre-occupation with other health issues, provider attitudes, inaccessible facilities and equipment, positioning, provider training, and health communication.

Conclusions

Improving screening rates requires a multifaceted approach at the federal, state, and local levels that improve environmental access, enhance provider training, increase outreach to women with disabilities, and improve health communication.

Implications for Practice

Women with disabilities must have equal access to health promotion, disease prevention, and medical services to optimize good health. Social workers play an important role in improving breast cancer screening services for women with disabilities. Better understanding of the barriers to cancer screening will lead to improved interventions directed at reducing morbidity and mortality among this population of women.

INDEX WORDS: Women, Disability, Breast cancer, Social work

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CHAPTER I

INTRODUCTION

Background

In recent years, women's health has emerged as a prominent public health priority. Research focused on women's health has led to valuable information about how and why certain diseases affect women disproportionately, predominantly, or differently than men. It has also led to a better understanding of the differential health risks faced by particular subpopulations of women, such as those who are members of racial and ethnic minority groups. Yet despite the increased awareness of women's health, research to date has not adequately addressed the health concerns of women with disabilities (Thierry & Cyril, 2004). Recent studies suggest that women with disabilities encounter many of the same health problems as women who are not disabled, yet they consistently report poorer health (Chevarley, Thierry, Gill, Nosek, & Ryerson, unpublished data; Iezzoni, McCarthy, Davis, & Siebans, 2000).

One in every five women living in the United States has a disability (Jans & Stoddard, 1999; McNeil, 2001). Everyone knows someone with a disability. Nevertheless, the health needs of women with disabilities are not fully acknowledged by our current healthcare system. Although there is a growing interest in women's health, research addressing the health of women with disabilities is a new and emerging field. Only within the past decade has an increasing number of researchers begun to examine the health of women with disabilities and address topics such as access to care, health care utilization, and the prevention of secondary conditions (Coyle & Santiago, 2002; Iezzoni et al., 2000; Rimmer & Liu, 2001; Stuifbergen & Roberts, 1997; Turk,

Geremski, & Rosenbaum. 1997; Turk, Rosenbaum, & Scandale, 2001; Vines & Shackelford, 1996; White, Figoni, Froehlich, & Marquis, 2001). And for the first time objectives on the public health needs of people with disabilities, including disabled women, are reflected in *Healthy People 2010* (U.S. Department of Health and Human Services (HHS), 2000).

Until recently, most public health activities have focused on the prevention of disability in the general population, not on activities to promote the health and well-being of those living with a disability. All members of the disability community should have equal access to health promotion, disease prevention, and the direct services they need to optimize their health. Yet women with disabilities continue to face substantial physical, economic, social, and attitudinal barriers to accessing comprehensive healthcare services. In addition, they have the extra responsibility of dealing with health concerns directly related to their disability (Becker, Stuifbergen, & Tinkle, 1997; Thierry, 1998; Veltman, Stewart, Tardif & Branigan, 2001).

One approach for improving the health status of women with disabilities is to increase access to clinical preventive services. Although only a few studies have examined the use of preventive health services for women with disabilities, results indicate that these women consistently do not receive preventive health services. A 1998 report on cervical and breast cancer screening among women with functional limitations (FLs) found that older women with FLs were less likely to have received a Papanicolaou (Pap) test or mammogram within the recommended guidelines (Centers for Disease Control and Prevention (CDC), 1998). A more recent study of health care utilization found that while most women with disabilities had seen a general practitioner within the past six months, a substantial proportion of these women had not received routine gynecological care in the preceding five years (Coyle & Santiago, 2002). Similarly, researchers in Boston found that women with major mobility problems were

significantly less likely to receive Pap tests and mammograms than women with no mobility impairments (Iezzoni et al., 2000). The same study reported that people with mobility impairments were as likely as others to receive pneumococcal and influenza immunizations but were less likely to receive additional services such as tetanus immunization. These studies confirm that more attention should be given to screening and preventive services for women with disabilities.

To date, our understanding of the barriers to preventive services experienced by disabled women is limited and is based largely upon anecdotal information. Of particular concern are the barriers associated with the provision of clinical preventive services, most notably cancer screening, for women with physical disabilities. Understanding the unique barriers associated with breast cancer screening among women with disabilities is the primary focus of this research.

Breast cancer is the second leading cause of death in women (American Cancer Society (ACS), 2004). In 2004, an estimated 215,990 new cases of breast cancer will be diagnosed in American women, and an estimated 40,110 women will lose their lives to this disease (ACS 2004). Research has shown that mortality due to breast cancer could be significantly reduced by making early detection and treatment services available to all women at risk (CDC, 1996; CDC, 1999). Unfortunately, research to date suggests that women with disabilities do not consistently receive these lifesaving preventive health services (CDC, 1998; Iezzoni et al., 2000; Thierry & Cyril; 2004).

Cancer has been the focus of nationwide educational campaigns to inform the public that the risk of cancer can be significantly reduced when adequate preventive measures are taken. Early detection also has an important impact on cancer mortality rates. Procedures such as mammography, clinical breast exam, and breast self exam make it possible to identify and treat

cancers at an early stage before they spread. Research suggests that breast cancer deaths could be reduced by 30 percent among women aged 50 - 69 through the use of mammography and clinical breast examination (Fletcher, Black, Harris, Rimer, & Shapiro, 1993; Shapiro, Venet, Strax, Venet, & Roeser, 1985; Taber, Gad, Holmberg, & Ljungquist, 1985; Verbeek, Hendricks, Holland, Mravunac, Sturmans, & Day, 1984). Women with disabilities, however, have not been the target audience for these health messages and campaigns.

To date, social work has played a limited role in disability policy, practice, and research (Beaulaurier & Taylor, 2001; DePoy & Miller, 1996; Gourdine & Saunders, 2002; Mackelprang & Salsgiver, 1996). Given social work's rich history in advocating for and providing services to other underserved populations, it is unclear why social work has not embraced the health issues of women with disabilities. Although articles addressing social work and breast cancer are available (Boynton & Thyer, 1994; Cwikel & Behar, 1999), none of these articles address the important role social work can play in breast cancer screening and treatment for women with disabilities. Yet, medical and public health social workers are in a unique position to influence public policy and the delivery of cancer screening and treatment services to this underserved population of women.

Purpose of the Study

The purpose of this study was to explore in depth the barriers to breast cancer screening and treatment among women with physical disabilities. This study was conducted using a basic qualitative approach with focus group interviews as the main data collection procedure. The project was a logical extension of the earlier CDC population-based study, which pointed to screening differences between women with and without functional limitations (CDC, 1998).

Although the earlier study provided evidence that women with disabilities were not being screened regularly, it offered few explanations as to why these disparities existed.

Research Question

The primary research question addressed by this study was “What are the barriers to breast cancer screening and treatment for women with physical disabilities?” Additional subquestions were asked to explore perception of risk; knowledge of clinical breast exam and mammograms; interactions with the health care system; preventive behaviors; perceptions of barriers; and strategies for improving screening among this underserved population of women. In addition, women who have undergone treatment for breast cancer were asked to describe their experiences from the time of initial diagnoses through the recovery process. Results of this study are expected to lead to improved interventions directed at reducing cancer mortality among women with disabilities. Implications for public health social work policy and practice will be discussed.

Funding

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CHAPTER II

LITERATURE REVIEW

This chapter provides an overview of the relevant literature addressing: women and disability; models of disability; breast cancer surveillance, risk factors, and guidelines for screening; levels of screening among women with disabilities; and social work and people with disability.

Definitions, Causes and Prevalence of Disability Among Women

In general terms, disability refers to “limitations in physical or mental function, caused by one or more health conditions, in carrying out socially defined tasks or roles” (Pope & Tarlov, 1991, p. 35). Commonly accepted measures of disability have focused on functional limitations, activity limitations, and work limitations. These definitions allow for the inclusion of people with many disabling conditions including sensory, cognitive, emotional, or physical impairments, and various chronic health conditions. However, use of these multiple definitions has resulted in varying prevalence estimates of disability in women. For example, estimates from the National Health Interview Survey-Disability Supplement (NHIS-D) indicate that 16% of women 18 years of age or older had at least one functional limitation (Chevarley et al., unpublished data). In comparison, state-based estimates from the Behavioral Risk Factor Surveillance System suggest the overall prevalence of disability among women is 18% (CDC, 2000).

Depending on the definition used, overall estimates of disability among women in the United States range from 19.9 to 28.6 million (LaPlante & Carlson, 1996; McNeil, 2001), or

approximately one in every five adult women. Disorders of the back and spine are the most prevalent conditions associated with disability among women followed by arthritis and heart disease (Laplante, 1996). Together, these conditions represent approximately 38% of all conditions causing limitations among women. Conditions generally thought to have a high risk for causing severe disability among women, such as multiple sclerosis, spinal cord injury, and mental retardation, have small prevalence rates, yet are often associated with greater severity of disability and increased need for specialized services (Altman, 1996).

Models of Disability

Several conceptual models of disability have been developed to describe disability-related concepts. The medical model of the 1950's viewed pathology as comparable to disability. By the mid 1970's, Nagi (1976) described a process by which pathology led to impairment, which could result in a limitation in function, which may then result in disability. Building upon the Nagi model, the Institute of Medicine (IOM) model, described by Pope and Tarlov (1991), defined disability as a function of the interaction between a person and his or her environment. These concepts were expanded upon by Brandt and Pope (1997) who emphasized the critical role the social and physical environments play in determining the amount of disability one experiences. Although there is no universally accepted theory of disability, these models are helpful in understanding the current direction of disability research in the United States today.

Breast Cancer Incidence, Mortality, and Survival Rates

Breast cancer is the most commonly diagnosed form of cancer in women and the second highest cause of cancer-related mortality among women in the United States (CDC, 2000). In the year 2004, an estimated 215,990 new cases of breast cancer will be diagnosed in American women, and an estimated 40,110 women will lose their lives to this disease (ACS, 2004). Data

from the National Cancer Institute's (NCI) Surveillance, Epidemiology, and End Results (SEER) program indicate that the incidence of breast cancer has increased from 82.6 cases per 100,000 women in 1973 to 110.7 cases per 100,000 women in 1996 (Ries, Kosary, Hankey, Miller, Clegg, Edwards & 1999). These incidence rates have remained relatively stable throughout the 1990s. For women, the lifetime risk of being diagnosed with breast cancer is 12.56% (Ries et al., 1999).

Breast cancer deaths among women are beginning to decline. In 1996, the age-adjusted mortality rate for breast cancer was 24.3 per 100,000 women, a slight decrease from 26.9% in 1973 (Ries et al., 1999). It is important to note that this represents the first sustained decline in breast cancer mortality rates since 1973 when SEER surveillance for breast cancer was established (CDC, 2000). For women, the lifetime risk of dying from breast cancer is 3.39% (Ries et al., 1999). A disproportionately higher number of these deaths will occur among minorities and women of low income (CDC, 1993; Institute of Medicine, 1999).

Overall, breast cancer incidence and mortality rates vary considerably among racial and ethnic groups. For example, white women are more likely to develop breast cancer than women of other racial and ethnic groups (CDC, 2000). Black women, however, are more likely to die of this disease (CDC, 2000).

Stage-specific survival rates vary considerably among racial and ethnic groups. From 1985 to 1989, the five-year relative survival rates for breast cancer were 86% for white women and 71% for black women (Greenlee, Murray, Bolden, & Wingo, 2000). Survival rates are the highest among women diagnosed in the early stages of the disease. The five-year survival rate for white women with localized breast cancer is 97%. If the cancer has spread regionally, the survival rate decreases to 78%. For those women with distant metastasis the chance of survival

drops to 22%. The rates for black women are 89%, 63%, and 14% respectively (Greenlee et al., 2000).

Survival after a diagnosis of breast cancer continues to decline beyond five years. Approximately 71% of all women diagnosed with breast cancer in 1996 will survive 10 years, 57% will survive 15 years, and 52% will survive 20 years (Ries et al., 1999). Screening mammography followed by timely and appropriate treatment can reduce breast cancer mortality by 30% for women 50-69 years of age (CDC, 1996; CDC, 2000; Fletcher et al., 1993).

Risk Factors

It is estimated that only 55% of all cases of breast cancer can be explained by known risk factors (Bruzzi, Green, Byar, Brinton, & Schairer, 1985). Risk factors are defined as “biological, environmental, and lifestyle or behavioral characteristics that are causally associated with health-related conditions” (Pope & Tarlov, 1991, p. 8). Established risk factors for breast cancer include: gender, age, family history of breast cancer, history of benign breast diseases, nodular densities on the mammogram, exposure to high-dose radiation, early age at menarche, late age at menopause, nulliparity, late age at first full-term pregnancy, obesity, white race, high socioeconomic status, and place of residence, particularly urban areas in the Northern United States (Briton, 1994; CDC, 2000; Kelsey, 1993). Associations between breast cancer and long-term use of oral contraceptives, extended and/or recent use of menopausal estrogens, alcohol consumption, and failure to breast-feed have been identified; however, causal relationships have not been firmly established. The role of environmental factors such as occupational exposures or electromagnetic radiation remains inconclusive (Briton, 1994).

A majority of women will have one or more risk factors for breast cancer. Unfortunately, most of the identifiable risk factors (e.g., familial susceptibility, menstrual

characteristics, reproductive behavior, demographic and socioeconomic factors) are not amenable to prevention. Recent studies, however, suggest that selective estrogen receptor modulators (SERMs) such as tamoxifen and raloxifene may reduce the risk of developing breast cancer (CDC, 2000). Preliminary results from clinical trials suggest that tamoxifen significantly reduces the probability of breast cancer in women at increased risk for the disease (Fisher, Costantino, Wickerham, Redmond, Kavanah, Cronin, Vogel, Robidoux, Dimitrov, Atkins, Daly, Wieand, Tan-Chiu, Ford, & Wolmark, 1998). Early detection, however, provides the best opportunity to reduce mortality.

Clinical Breast Exam, Mammography, and Breast Self Exam

Clinical breast exam (CBE), mammography and breast self-exam (BSE), are the primary procedures used for the early detection of breast cancer (U.S. Preventive Services Task Force, 1996). Multiple clinical trials have demonstrated the effectiveness of screening with mammography and/or clinical breast examination (Fletcher et al., 1993; Kerlikowske, Grady, Rubin, Sandrock, & Ernster, 1995). Evidence to date suggests that mammography screening does not significantly reduce breast cancer mortality for women aged 40-49. All the clinical trials, however, showed reductions in mortality ranging from 20% to 39% for women aged 50 and older (Fletcher et al., 1993; Kerlikowske et al., 1995). Data for women aged 70 or older are insufficient to judge the effectiveness of screening. Data regarding the effectiveness of BSE are limited and appear to be inferior to CBE and mammography (U.S. Preventive Services Task Force, 1996).

Guidelines for Screening

Mammography is the primary procedure used for breast cancer screening. A meta-analysis of the trials conducted by Kerlikowske et al. (1995) suggests that optimum cost-

effectiveness for mammography screening may be achieved by screening women every two years without diminishing the potential benefit of screening. Recommendations for screening can be confusing and vary according to professional organizations. The U.S. Preventive Services Task Force (1996) recommends a screening mammogram every 1-2 years for women aged 50-69 years. In addition, physicians can recommend that high risk women aged <50 years receive a screening mammogram. The National Cancer Institute's 1997 mammography guidelines recommend screening mammograms every 1-2 years for women aged ≥ 40 years if they are at average risk for breast cancer (Eastman, 1997). Despite the scientific evidence to date, recently revised American Cancer guidelines recommend annual mammography for all women aged ≥ 40 years (Leitch, Dodd, Constanza, Linver, Pressman, McGinnis, & Smith, 1997).

Cancer Treatment

Treatment may involve lumpectomy (local removal of the tumor) and removal of the lymph nodes under the arm; mastectomy (surgical removal of the breast) and removal of the lymph nodes under the arm; radiation therapy; chemotherapy; or hormone therapy (NCI, 1998). Often two or more methods are used in combination. Numerous studies have shown that, for early stage disease, long-term survival rates after lumpectomy plus radiotherapy are similar to survival rates after modified radical mastectomy. Significant advances in reconstruction techniques provide several options for breast reconstruction after mastectomy. In recent years, this often has been performed at the same time as mastectomy. High dose chemotherapy with bone marrow transplant or stem cell rescue is a new treatment under study for special cases of breast cancer (NCI, 1998).

Levels of Screening Among Women with Disabilities

National data on breast cancer screening for women with disabilities are limited. In October 1998, the CDC released a report on the use of cervical and breast cancer screening among women with functional limitations (FLs)(CDC, 1998). The report provided an analysis of linked data from the 1994 National Health Interview Survey Disability Supplement (NHIS-D) and the 1994 Health Promotion Disease Prevention Year 2000 Objectives Supplement. CDC found that among the total sample of women 40 years or older, approximately 76% had had at least one mammogram. Among women aged 65 years or older, however, those with three or more FLs were less likely than those without FLs to have ever had a mammogram and were significantly less likely to have had a mammogram within the previous 2 years.

Findings from this study showed that, although the percentages of all women who had had mammograms were below the percentages set as goals in the national objectives, the gaps between the desired percentages and actual percentages screened were larger for women with FLs than for other women. Women with FLs who were older had an increased probability of not having recommended screenings. Similarly, researchers in Boston found that women with severe mobility impairments were significantly less likely to receive Pap tests and mammograms than women with no mobility impairments (Iezzoni et al., 2000).

Barriers to Screening

Cultural values, health beliefs, attitudes, and the physical environment can affect screening use behaviors. Lack of perceived susceptibility, lack of physician referral, and concerns about radiation, pain, cost, and access have been associated with lower rates of mammography utilization in the general population (HHS, 2000; Rimer, 1995). Few studies are

available regarding the use of screening tests among women with disabilities. Thus, much information on this topic remains anecdotal.

In general, women with disabilities face substantial barriers that limit their access to health care services. These include physical, attitudinal, and policy barriers; lack of information about how disability affects health; limited finances; and insufficient personal assistance (Thierry, 1998). Although these barriers are beginning to be addressed through laws such as the Americans with Disabilities Act (PL-101-336), they remain prevalent in our society.

Several unique physical and attitudinal barriers have been reported to reduce the likelihood that women with disabilities will receive recommended preventive screenings. These include lack of accessible transportation, inaccessible equipment and facilities, difficulty mounting standard examination tables, difficulty with positioning during examinations, and lack of provider knowledge regarding disability (Becker, Stuijbergen, & Tinkle, 1997; Nosek, & Howland, 1997; Thierry, 2000).

Provider attitudes may be the most difficult barriers to overcome (Becker, Stuijbergen, & Tinkle, 1997; Thierry, 2000). Women with disabilities are often considered asexual (Fine, Asch, 1988; Krotoski, Nosek, & Turk, 1996), and providers may have the misconception that these women do not need regular gynecological care or that it is impossible to perform a comprehensive examination because of the woman's disability. A recent study by Coyle and Santiago (2002) found that while most women with disabilities had seen a general practitioner within the past six months, a large percentage of these women had not received routine gynecologic care in the previous five years. Although few medical offices use them, adjustable-height examination tables and accessible mammography equipment are available that

accommodate most women with disabilities (CDC, 1998; Welner, 1998; Patented Wheelchair Accessible Powermatic Examination Table, Lorad Contour 2000).

Most health care professionals have not been adequately trained to address problems and issues related to disability. As women with disabilities live longer, clinicians must recognize that these women also benefit from the full range of preventive health services. Personal correspondence with the American College of Obstetricians and Gynecologists revealed that most OB/GYN's receive little or no formal training in medical school or their residency program on the reproductive needs of women with disabilities. Education of providers of screening services regarding the special healthcare needs of women with disabilities, techniques for conducting gynecologic examinations and mammograms that accommodate disabled women, and training in the management of disability-related symptoms that may interfere with examinations is critical (CDC, 1998).

Behavioral-based interventions that help women with disabilities overcome personal and environmental barriers may be necessary to encourage these women to seek screening. This study will attempt to describe the full range of barriers disabled women face in obtaining breast cancer screening and treatment services. Better understanding of these critical barriers will lead to improved interventions directed at reducing cancer mortality among women with disabilities.

Social Work and People with Disabilities

To date, social work has played a limited role in disability policy, practice, and research (Beaulaurier & Taylor, 2001; DePoy & Miller, 1996; Gourdine & Saunders, 2002; Mackelprang & Salsgiver, 1996). Given social work's rich history in advocating for and providing services to other underserved populations, it is unclear why social work has not embraced the health issues of people with disabilities, and disabled women in particular.

In general, there is a paucity of information in the social work literature addressing disability. Much of the published literature focuses on the special needs of children with developmental disabilities and their families (Hanley & Parkinson, 1994; Malone, McKinsey, Thyer & Straka, 2000). Many of the articles are outdated, continue to use inappropriate language, and foster dependency among the individuals the profession claims to serve (Ell, 1985; Quinn, 1995; Taylor & Taylor, 1996).

Since the passage of the Americans with Disabilities Act, articles discussing the lack of disability content in the social work curriculum have emerged (DeWeaver & Kropf, 1992; Orlin, 1995; Depoy & Miller, 1996; Gourdine & Sanders, 2002). These articles continue to debate the best methods for including the required content into the social work curriculum: infusion or disability-specific electives. Despite these discussions, very few schools of social work offer disability content in their curriculum and those who do, do so primarily through field instruction experiences (DePoy & Miller, 1996; Gourdine & Saunders, 2002).

Although articles addressing social work and breast cancer are available (Boynton & Thyer, 1994; Cwikel & Behar, 1999), none of these articles address the important role social work can play in breast cancer screening and treatment for women with disabilities. Yet, medical and public health social workers are in unique positions to influence public policy and the delivery of cancer screening and treatment services to this underserved population of women.

CHAPTER III

RESEARCH METHODS, DATA COLLECTION & ANALYSES

The purpose of this study was to explore the barriers to breast cancer screening among women with physical disabilities. This chapter provides an overview of the methods used to explore, in depth, a variety of barriers that may impact screening behaviors among this underserved population of women.

Design

This study is a logical extension of an earlier quantitative study examining breast cancer screening among women with and without functional limitations (FLs) in the United States (CDC, 1998). The initial study used population-based data to determine the percentage of women with disabilities who received a mammogram and compared these women to women without disabilities. While these data helped to define the magnitude of the problem in the United States, they were insufficient to determine why screening disparities existed, particularly among older women with three or more FLs.

This study was conducted using a basic qualitative approach with focus group interviews as the main data collection procedure. This approach was chosen because research on this topic was limited and it seemed to be the best method for exploring and understanding the barriers to screening experienced by disabled women. The goal was to provide insight into the attitudes, perceptions, and behaviors of women with physical disabilities regarding breast cancer screening and treatment. Focus group procedures were selected because they are both practical and useful in uncovering factors related to complex issues such as cancer screening and disability. Findings

from the study will be used to identify and remove barriers and improve breast cancer screening and treatment for women with physical disabilities.

In recent years focus groups have become an important research tool in the applied social and behavioral sciences. Krueger (1994) defines a focus group as “a carefully planned discussion designed to obtain perceptions on a defined area of interest in a permissive, non-threatening environment”(p. 6). According to Brown (1999):

The focus group technique needs to be distinguished from other types of group interviewing, such as the nominal group technique, which brings together the ideas of individual participants; the Delphi technique, which relies on the collective opinion of an expert panel; and brainstorming sessions, which seek to generate new ideas and creative problem solving (p. 112).

Furthermore, focus groups do not promote consensus building or decision-making, rather, the intent is to gather information based on the participants’ interactions.

For this study, focus group interviews were selected as the most appropriate methodology for several reasons. Focus groups are considered a socially oriented research method and thus capture real-life data in a social environment. Throughout the group, participants are influencing and influenced by the comments of others—just as they are in real life.

Disability is a complex issue and women with physical disabilities are the most knowledgeable source of information regarding their barriers to participation in breast cancer screening and treatment. Focus groups offer a mechanism for hearing individual stories, encouraging participants to reflect on their experiences, and react to each other’s insights. Focus groups provide an opportunity to explore these stories while simultaneously probing for common

themes and experiences. This flexibility to explore unanticipated issues is not possible with more structured methodologies (Krueger, 1994).

In contrast to quantitative research methods that ask “How many?” and “How often?” focus groups help to answer research questions emanating from the question “Why?” In this case, these include questions about why women with disabilities do or do not obtain mammograms. Like individual interviews, focus groups offer an opportunity to explore the subtleties of individuals’ views and responses. According to Morgan and Spanish (1984):

.... the strengths of focus groups come from the compromise between the strengths found in other qualitative methods. Like participant observation, they allow access to a process that qualitative researchers are often centrally interested in: interaction. Like in-depth interviewing, they allow access to the content that we are often interested in: the attitudes and experiences of our informants. As a compromise, focus groups are neither as strong as participant observation on the naturalistic observation of interaction, nor as strong as interviewing on the direct probing of informant knowledge, but they do a better job of combining these goals than either of the two techniques (p. 260).

Focus groups have been reported to have high face validity (Krueger, 1994). The technique is easily understood, and the results seem believable to those using the information. In addition, focus group discussions can be relatively low cost and provide fairly quick results. Finally, focus groups can enable the researcher to increase the sample size without increasing the time required to collect additional data.

Despite these strengths, focus groups have methodological limitations. The findings are not quantitative and cannot be generalized to the population at large. Focus group results are suggestive, rather than definitive. They rely on group, not individual analyses. They should be

used to enrich an understanding of an issue, rather than to unequivocally support a particular position.

Interpreting and analyzing focus group comments can be difficult and requires a certain tolerance for ambiguity. For example, focus group transcripts may not capture every comment due to a combination of soft-spoken participants and the quality of the audiotape. Some women may repeat statements and themes throughout transcripts, causing the researcher to overestimate the occurrences of certain themes. Likewise, since we cannot count the quiet agreement and nodding heads of participants, there may be an underestimation of the prevalence of certain feelings or themes among group members. Another difficulty lies in differentiating between individual comments by separate participants, and repeated comments by the same participant. For this reason, raw “counts” of the number of times a word or concept is mentioned should not be the primary basis for focus group findings. Most importantly, all comments must be analyzed within the context of the social environment. Therefore, care is needed to avoid taking comments out of context and coming to premature conclusions (Krueger, 1994).

Depending on the population of interest, focus groups may be difficult to assemble and can vary considerably. One group can be energetic and eager to share their experiences, while another group can be quiet and reluctant to participate. In addition, the value of focus groups relies heavily on the moderator’s skill in managing the group in such a way that a range of representative views can emerge. For the moderator, this represents a challenge not only in probing for details, but also in knowing how and when to steer the conversations back to the research questions if a participant’s comments should drift off course.

Despite these constraints, focus group interviews can yield valuable insights that are difficult or impossible to glean through other data collection techniques. These insights are

important in their own right, but they can also be applied in shaping and refining more rigorous, quantitative studies.

Collaborators/Funding Sources

The Federal Coordinating Council on Breast Cancer Research and the CDC, National Center on Birth Defects and Developmental Disabilities (NCBDDDD), Disability and Health Program funded this project. It was a collaborative effort with the Center for Research on Women with Disabilities (CROWD) at Baylor College of Medicine, and the University of Kansas Lifespan Institute at the Research and Training Center on Independent Living.

Using a collaborative team to assist with this research project had both advantages and disadvantages. First, because disability is a complex issue, it was imperative that people with disabilities, particularly women with disabilities, participate in all phases of the research. In this study, four of the five team members had physical disabilities; four were also women. Second, the team members were nationally recognized and respected researchers with strong ties to the disability community. Several of the researchers had well-established relationships with numerous Centers for Independent Living (CILs) throughout the country, thus increasing our ability to recruit participants. Third, members of the team co-moderated the focus group discussions and provided valuable feedback during data analyses. Finally, they are expected to be instrumental in disseminating the final results of this study throughout the disability community. The major disadvantages in using this approach were the number of people involved in the project and the time needed to coordinate activities across multiple settings.

Selection Criteria

Women, aged 40 years and older with physical disabilities, were purposefully recruited to participate in 12 focus groups conducted in seven locations throughout the United States. In

this study, physical disability was defined as limitations in physical function (e.g., walking, lifting, getting dressed), caused by one or more health conditions, which interfered with a person's ability to carry out socially defined tasks or roles.

Fifty-two women with physical disabilities participated in the study. An attempt was made to recruit women with a variety of disabling conditions including but not limited to spinal cord injury, cerebral palsy, muscular dystrophy, polio/post polio, stroke, spina bifida, multiple sclerosis, joint and connective tissue disease (e.g., lupus, scleroderma, or arthritis), traumatic brain injury with loss of physical function, and amputation. Participants needed to be disabled for a minimum of three years so they could discuss the issues associated with cancer screening, diagnosis, and treatment within the context of their disability. Information collected about primary disabling condition(s) and length of time since disability was based on participant self-report.

The decision to select homogeneous or heterogeneous groups of participants for focus groups has been debated in the literature (Brown, 1999; Patton 1990). Homogeneous groups were chosen for this study because all focus group participants shared the disability experience as well as similar cancer screening behaviors. However, in an effort to gather multiple perspectives on the issues, focus groups were conducted in different geographical locations (urban versus rural), and an attempt was made to reflect the cultural and ethnic composition of the population.

Eligible participants were assigned to one of three groups: Group A, women with physical disabilities who had never received a mammogram or had not received a mammogram within the recommended guidelines (>2 years); Group B, women with disabilities who had received a mammogram within the recommended guidelines (≤ 2 years); and Group C, women

with physical disabilities who had survived breast cancer. This represents a reconfiguration from the original study protocol, which assigned only women who had never been screened to group A. This reconfiguration, which was approved by all four institutional review boards, was necessary due to our difficulty in recruiting participants who had never been screened. Of the first 40 eligible participants, only one woman indicated that she had never been screened for breast cancer. This may have been due to a lack of interest in this study by women who did not perceive themselves as being at risk for breast cancer. It could have also been a result of social desirability bias, as many women over the age of 40 may not want to admit that they have never received a mammogram.

The research of Krueger (1994) and others (Brown, 1999) suggests that groups tend to fragment when their size exceeds 12 participants; therefore the maximum number of women assigned to each group was 10. The groups were small enough so participants would have sufficient time to express their individual views, yet large enough to generate a diversity of responses.

There does not appear to be a consensus among researchers regarding the maximum number of focus groups that can comprise a study. The most important issue to consider is how many groups are required to reach a point of saturation. Saturation occurs when no additional information is uncovered. According to Brown (1999), when focus groups are the primary means of data collection, 4-5 focus groups may be required to reach saturation. Over the course of this study, a total of 12 focus groups were conducted.

Most focus groups last approximately 1-2 hours. According to Tang (1995), groups that meet less than one hour run the risk of not fully exploring the topic of concern and when the groups go beyond 2 hours, participants often become fatigued or disinterested. The potential for

fatigue was a very real concern given our target audience of women with physical disabilities therefore; we did our best to keep each focus group to a maximum of two hours. Surprisingly, many of the women wanted to continue the discussion beyond the two-hour time allotment. Many of these women indicated that this was a very important issue and the public health community typically does not solicit their opinions. They were grateful for the opportunity to share their experiences and wanted to be heard.

Focus Group Locations

The 12 focus groups were conducted across seven different Health and Human Services (HHS) regions throughout the United States. All focus groups were held in selected Centers for Independent Living (CILs) or alternative sites (e.g., hospital or clinic settings) in California (Region IX), Colorado (Region VIII), the District of Columbia (Region III), Massachusetts (Region I), Minnesota (Region V), Mississippi (Region IV), and Texas (Region VI). (See Figure 1). Colorado, the District of Columbia, Minnesota, and Mississippi each hosted two focus groups, an A group and a B group. California, Massachusetts and Texas were the sites for all treatment groups (Group C). Two treatment groups were held in Texas and one treatment group was held in California and Massachusetts (See Figure 2).

Although Massachusetts hosted a focus group, significant problems were encountered with recruitment and only one person participated. Since this person did not perceive herself as having a disability and was unable to answer questions within the context of her disability, data from that focus group was not included in the analyses.

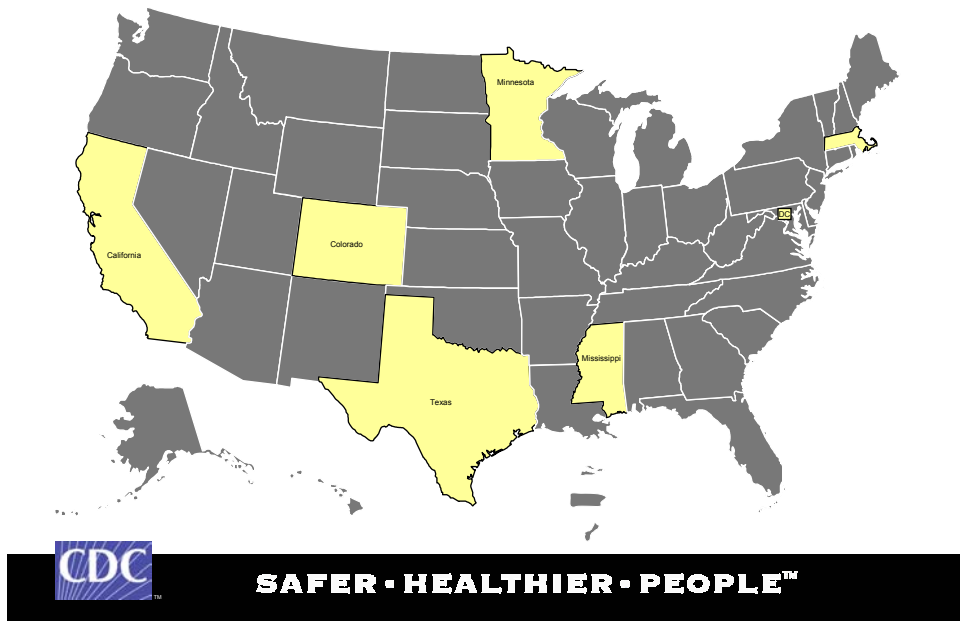


Figure 1: Map

Focus Group Composition

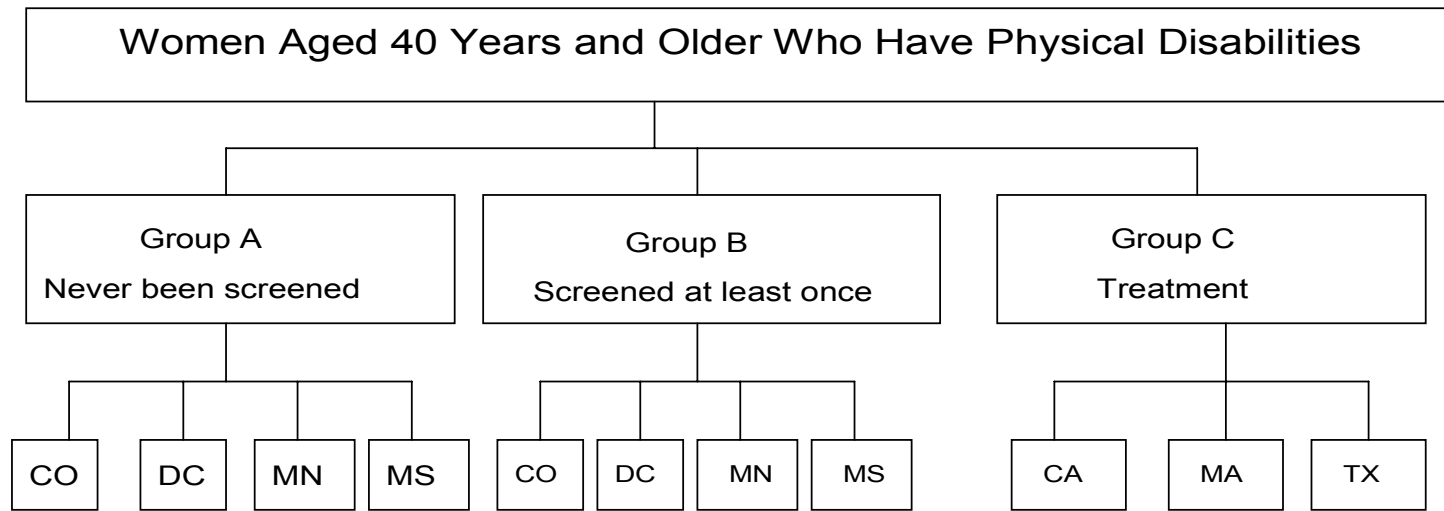


Figure 2: Focus Group Composition

The majority of the focus groups were conducted in Centers for Independent Living (CILs). These CILs are not residential programs. They are private, consumer-driven, nonprofit corporations that provide services to maximize the independence of individuals with disabilities. Core services include the following: advocacy, independent living skills training, information and referral, and peer counseling. There were several advantages to working with the CILs. First, they are federally funded and therefore located in every state, in both urban and rural settings. Second, they serve adults with a variety of disabling conditions and are trusted by the disability community. Third, each center had sufficient on-site space to comfortably conduct the focus groups. And finally, they were fully accessible and familiar to the women attending the groups.

Criteria used in selecting the focus group locations for this study included: federal region, setting (i.e., urban or rural), cultural and ethnic representation, breast cancer mortality rates, perceived strength of the CIL (e.g., client base, prior research experience, infrastructure), interest in women's health issues, and personal contacts as illustrated in Table 1.

At the time of this study, demographic information on disability and ethnicity was determined from 1990 Census information and updated using the 1994 demographic estimates developed by the National Planning Development Corporation (Mathews, Nunley, Dawson, & Henh, 1994), the best available data at that time. (Insert Table II - Disability & Ethnicity). It was expected that a higher number of African Americans would be recruited in Mississippi and the District of Columbia as both CILs served an ethnically diverse population of people with disabilities. Likewise, it was expected that Hispanic representation would be highest in Texas and California.

Table 1

Location Decision Chart

State	HHS Region	Setting	Ethnic Representation*	Mortality Rates (range)	CIL Infrastructure	Interest in Women's Health	Contacts
California	IX	Urban	Hispanic, Asian	25.4 (Medium)	Strong	Yes	Yes
Colorado	VIII	Urban & Rural	White, Hispanic	23.8 (Low)	Strong	Yes	Yes
District of Columbia	III	Urban	Black	33.9 (High)	Strong	Yes	Yes
Massachusetts	I	Urban & Rural	White	29.6 (High)	Strong	Yes	Yes
Minnesota	V	Rural	White	25.6 (Medium)	Strong	Yes	Yes
Mississippi	IV	Rural	Black	23.7 (Low)	Strong	Yes	Yes
Texas	VI	Urban & Rural	Hispanic	24.1 (Low)	Strong	Yes	Yes

*The number of people with disabilities who identify with these groups is high.

Table 2

Demographic Information on Disability and Ethnicity United States Non-Institutionalized Population, Over the Age of 16, 1994

State	Total 1994 Population	Estimated Number of People with Disabilities	White	Black	Hispanic*	Native Am.	Asian
California	31,546,601	1,588,161	1,252,849 (79%)	131,412 (8%)	462,251 (29%)	14,778 (1%)	189,119 (12%)
Colorado	3,630,585	131,576	120,341 (91%)	6,884 (5%)	22,073 (17%)	1,375 (1%)	2,977 (2%)
District of Columbia	571,592	42,990	13,759 (32%)	28,134 (65%)	2,853 (7%)	111 (<1%)	986 (2%)
Massachusetts	6,012,972	576,283	518,081 (90%)	39,323 (7%)	33,844 (6%)	1,282 (<1%)	17,597 (3%)
Minnesota	4,550,733	259,273	241,660 (93%)	7,740 (3%)	3,821 (1%)	3,137 (1%)	6,731 (3%)
Mississippi	2,659,929	199,518	122,704 (62%)	74,996 (38%)	1,277 (<1%)	795 (<1%)	1,024 (<1%)
Texas	18,276,705	890,033	755,991 (85%)	110,816 (12%)	254,045 (29%)	3,646 (<1%)	19,551 (2%)

Estimated Number of People with Disabilities: the number of people included in the total 1994 population who have a disability as estimated from three Census questions regarding disability.
Race: the number of people with disabilities who identified themselves as White, Black, Hispanic* (includes Whites & Blacks), Native American (includes American Indian, Eskimo, or Aleut), and Asian or Pacific Islander.

Source: Mathews RM, Nunley RE, Dawson RW and Henh JC (1994). Demographic information on disability and ethnicity: Geodemographic maps. Research and Training Center on Independent Living. University of Kansas. NIDRR Grant Hi33B30012-94A.

Access to breast cancer screening varies by geographic location and setting. Therefore focus groups were conducted in both urban and rural areas. For example, CILs in Minnesota and Mississippi who serve predominately rural communities were selected to participate in this study. The District of Columbia, California, and Texas were chosen for their large urban areas.

Sites were also selected according to the most recent breast cancer mortality rates available at the time. Data on breast cancer mortality, as illustrated in Table 3, were derived from the National Center for Health Statistics (Ries, Kosary, Hankey, Miller, HARRAS, & Edwards, 1997). At the time of the study, the average annual age-adjusted breast cancer mortality rate in the U.S. was 26.4 per 100,000. As indicated in Table 3, the District of Columbia had the highest breast cancer mortality rate (33.9) in the country, with a 28.4% difference between the district rate and the total U.S. rate. Similarly, Massachusetts ranked number 4 with a rate of 29.6. Texas, Colorado, and Mississippi had some of the lowest breast cancer mortality rates in the country (24.1, 23.8, 23.7), ranking 43, 45, and 46 respectively.

Finally, each CIL or hospital/clinic had some experience addressing health concerns of people with disabilities or had expressed an interest in working in the area of women's health. All decisions regarding CIL infrastructure and level of interest were based on prior knowledge, personal communication, and previous interactions with center staff and reflect the bias of the research team.

Recruitment

Participant recruitment is one of the most important parts of any research study. In this study, recruitment activities fell largely upon the staff of Baylor College of Medicine, the University of Kansas, and the local CILs or hospital/clinic-based sites. The benefit of using staff from these centers was that they were recognized leaders in their communities and would be able

Table 3

Female Breast Cancer (Invasive) Average Annual Age-Adjusted Cancer Mortality Rates by State, 1990-94

All Races, Females

<u>State</u>	<u>Rate</u>	<u>SE</u>	<u>Rank</u>	<u>PD</u>
(Total U.S)	26.4	0.06		
California	25.4 [⊗]	0.18	(30)	-3.8
Colorado	23.8 [⊗]	0.51	(45)	-9.8
District of Columbia	33.9 [⊗] ◇	1.36	(01)	28.4
Massachusetts	29.6 [⊗]	0.40	(04)	12.1
Minnesota	25.6	0.45	(24)	-3.0
Mississippi	23.7◇	0.56	(46)	-10.2
Texas	24.1 [⊗]	0.23	(43)	-8.7

Rates National Center for Health Statistics (NCHS). Rates are per 100,000 and are age-adjusted to the 1970 U.S. standard population.

SE Standard error of the rate

PD Percent difference between state rate and total U.S. rate

◇ Absolute difference between state rate and total U.S. rate is 10% or more

⊗ Difference between state rate and total U.S. rate is statistically significant ($p \leq .0002$)

Source: Ries LAG, Kosary CL, Hankey BF, Miller BA, Hurray A, Edwards BK. (1997). SEER Cancer Statistics Review, 1973-1994, National Cancer Institute. NIH Pub.No. 97-2789. Bethesda, MD.

to use their personal contacts and consumer databases to recruit women with disabilities for the study. Kreuger (1994) points out that a danger of using non-researchers to recruit participants is that local staff may resort to selecting people they know just because they are easy to recruit. To prevent this, a special Recruitment Handbook was developed to assist communities in systematically recruiting participants for this study.

The handbook contained four easy-to-follow steps for developing a complete recruitment plan, including the explicit criteria and related protocols for initial screening and follow up. Participants could be recruited through a variety of strategies (e.g., accessing mailing lists, writing articles in newsletters, posting flyers, contacting community organizations), which were outlined in the handbook. Also included in the handbook were sample flyers, press releases, fact

sheets, and other useful resources. These materials could be used as they were or modified to meet specific community recruitment goals. (See Appendix A)

Prior to beginning the actual recruitment, all host organizations and research staff participated in a series of telephone conferences to review the research study, clarify individual roles and responsibilities, address recruitment strategies, and discuss all study protocols. Individual or group concerns were also addressed at that time.

Recruitment, particularly among hard to reach populations such as women with disabilities, often takes longer than expected and requires over recruitment to ensure a sufficient number of group participants. It was anticipated that disabled women might cancel at the last minute due to unexpected health issues, lack of personal care, or transportation issues. Therefore, centers were asked to recruit a minimum of 20 participants per focus group.

Despite our best efforts, several difficulties with recruitment were encountered which caused delays in the study. First, it was more difficult than originally anticipated to find women with disabilities who met the study criteria for Groups A and C. As previously mentioned, Group A was reconfigured to address these recruitment issues. In addition, it was extremely difficult to locate women who had been diagnosed and treated for breast cancer. Fifteen women met the study criteria for group C and agreed to participate, however, only 11 women actually participated in the focus groups. Of these women most could name other disabled women who had battled breast cancer. Unfortunately, these women did not survive.

The CILs themselves underestimated the time it would take and their ability to recruit participants for the study. Initially, many used passive recruitment efforts such as distributing or posting flyers in their center or placing information in their newsletters. Although this resulted in some participants, it was not sufficient. In response, the research team held frequent

conference calls with the local coordinators to offer support, discuss recruitment challenges, and brainstorm strategies for improving outcomes. Across all sites, the most effective method for recruiting participants required searching the center databases for women older than 40 and having the local coordinators call these women, briefly describe the study, and personally invite them to participate. This was very time intensive but proved to be quite successful.

Finally, disruptions associated with the September 11th terrorist attacks on our nation resulted in time delays and lost participation due to rescheduling. Tuesday morning, September 11th, focus group B was underway in Washington, DC. Immediately following the terrorist attack on the Pentagon, all office buildings, community-based organizations, private industry, and transportation systems were shut down. After discussing the situation, focus group participants agreed to continue our discussion until the CIL could arrange for accessible transportation to bring them home. The focus group only lasted 52 minutes and all participants were paid for their participation. We were unable to return to DC at a later date to complete the interviews or re-contact participants due to IRB restrictions.

As a result of these attacks, part of the research team was stranded in DC for a week and had to cancel scheduled trips to Colorado and California. Although the Mississippi focus groups were held as scheduled on September 21st and 22nd, the research team had to drive to the host location due to federally imposed travel restrictions. In addition, the grant covering this project was to expire October 1st, 2001, and a special, emergency request had to be filed to extend the data collection portion of this study through December 31, 2001. Rescheduling, particularly in Colorado, resulted in a loss of confirmed participants who were unable to participate on the alternate dates thus decreasing the overall sample size for the study.

Recruitment Procedures

Women who expressed an interest in the study were given a brief explanation of the research and asked about their interest in participating (See Appendix A, page 19). Those who were interested were asked a series of screening questions (i.e., age, race/ethnicity, disability, age of onset of disability) to determine whether or not the preliminary study criteria were met (See Appendix A, page 23). If these criteria were met, the CIL or hospital staff member obtained permission to record their contact information (i.e., name, address, phone number, and e-mail), and forward it to a member of the CDC Research Team at Baylor or Kansas (See Appendix A, page 27). A member of the research team would contact the potential participants to assess breast cancer screening and treatment history and determine eligibility (See Appendix A, page 31). This information was used by the CDC Research Team to assign participants to the appropriate focus group or place them on the alternate list. The CDC Research Team made the final decisions about eligibility. If a woman was not eligible for the study, a designated member of the research team destroyed her screening forms. All identifying information was kept at Baylor College of Medicine or the University of Kansas. To protect participants' confidentiality, CDC did not have access to personal identifiers. If selected to participate, the women were asked whether they could attend a focus group discussion on a particular date and whether they required transportation assistance or other reasonable accommodations.

The CDC Research Team assigned all eligible participants to one of three focus groups: Group A, women with physical disabilities who have never received a mammogram or have not received a mammogram within the recommended guidelines (>2 years); Group B, women with physical disabilities who have received a mammogram within the recommended guidelines (≤ 2 years); and Group C, women with physical disabilities who have survived breast cancer.

Independent living center staff, hospital, or clinic staffs were responsible for arranging special transportation and other reasonable accommodations for participants. They were also responsible for sending out an official letter of invitation that outlined the date, time, and location of the focus group (See Appendix A, page 35), and placing a reminder call to each participant 48 hours before the focus group (See Appendix A, page 39). During that contact, transportation schedules and reasonable accommodations were reconfirmed. In addition, local staff members maintained a waiting list of participants in the event that someone canceled (See Appendix A, page 43) and after the completion of the focus groups sent a follow-up thank you letter to all participants (See Appendix A, page 47).

Each CIL, hospital, or clinic was paid \$1,000 for their recruitment efforts. This was intended to help reimburse them for the hours they spent recruiting participants, arranging transportation or other special accommodations, and using their facilities to host the focus groups. Because of the difficulty in recruiting women with disabilities, each site was paid the full \$1,000 regardless of the number of women recruited for the study. At the conclusion of the study, most of the CILs indicated that they had significantly underestimated the staff time it took to recruit participants and although they would participate in future studies, additional funds would be needed to cover staff expenses.

Focus Group Procedures and Content

The focus group moderator plays a critical role in the conduct of successful focus groups. In this study, two trained female moderators conducted all 12 focus groups. The principal investigator served as the primary moderator for each location. One of three assistant moderators was assigned to each location. To help put participants at ease, the assistant moderators each had a physical disability. All moderators were skilled in focus group research techniques. A benefit

of having two moderators was that one moderator could record field notes and observe the nonverbal communication that was taking place while the other moderator facilitated the discussion. Because the study was conducted in 7 states, it was not possible to have the same assistant moderators in all seven states. The assistant moderators were selected from the CDC Research Team based on geographical region, physical disability, and race/ethnicity. Appendix B outlines the roles and responsibilities of the moderators and assistant moderators.

An outline and Moderator Discussion Guide were prepared to steer the focus groups (See Appendix C and D). The document was used as a guide only, not a script from which the moderators read questions verbatim. The moderators adapted the wording of the questions and the order in which they were introduced to best suit each group of women. The guide covered several topic areas including: general attitudes, practices, and experiences regarding health care; understanding risk and frequency for clinical breast exams and mammograms; reasons for not getting screened; experiences with breast exams and mammograms; response to results of mammogram; and experiences with diagnosis and treatment. The topics were discussed using the standard sequence of opening questions, transition questions, key questions and ending questions described by Krueger (1994). In addition, field notes were collected and recorded on a separate form. (See Appendix E).

At the conclusion of each focus group, the moderators provided printed materials, including information on local breast cancer resources that participants could take home with them. In Mississippi, a local breast cancer expert was available at the conclusion of the group to answer any cancer-related questions or concerns participants had at that time.

Incentives

Participation in focus groups, particularly for people with disabilities, often requires considerable time and energy. Money and food are frequently used incentives in focus group research. In addition to providing light refreshments, each participant received a \$30.00 stipend at the conclusion of the focus group. This was to help repay the women for their time and any additional costs associated with coming to the study. This falls within the acceptable range of payment (\$20-\$50) typically used for most public and nonprofit studies (Krueger, 1994). To assure participants were able to get to the focus group locations, reimbursement for transportation, including any special accommodations, was also provided.

Validity and Reliability

According to Creswell (1998) “Multiple perspectives exist regarding the importance of verification in qualitative research, the definition of it, and procedures for establishing it”(p. 197). Authors such as Lincoln and Guba (1985) have identified qualitative equivalents, or “alternative terms” that resemble traditional quantitative approaches to validity. To establish the trustworthiness of a study, these authors use the terms “credibility,” “transferability,” “dependability,” and “confirmability” as the qualitative equivalents for internal validity, external validity, reliability, and objectivity.

Several procedures exist to improve the trustworthiness of a study, these include persistent observation, triangulation of methods, peer review or debriefing, negative case analysis, clarifying researcher bias, member checks, thick description, and external audits. To enhance credibility, Creswell (1998) recommends using a minimum of two of these techniques in any given study. In this study, several of these procedures were used in varying degrees to establish credibility, transferability, dependability, and confirmability of the proposed study.

Credibility was addressed through member checks with participants and peer debriefing (Creswell, 1998). At the end of each focus group discussion, the assistant moderator provided a brief summary of participant responses to the most important questions discussed. Participants were given the opportunity to offer additions or corrections to the summary statements (member checking). Issues that required further discussion were addressed at that time. Although some additions were made, participants generally commented on the quality of the summaries. In addition, debriefing between the moderator and assistant moderator occurred immediately following each of the focus groups. During this time, the moderators documented their first impressions and highlighted similarities and differences observed from earlier focus groups.

The trustworthiness of any qualitative study is highly dependent on the credibility of the researchers because the researchers are the instruments for data collection and the center of the analytic process. All findings, interpretations, and conclusions are filtered through their theoretical position and biases. In this study, reliability rested heavily upon the training and credibility of the co-investigators, who were viewed as respected and knowledgeable members of the disability community. Although the researchers were highly qualified, all the assistant moderators were women with physical disabilities who had personal experiences, both positive and negative, with mammography screening.

Dependability was also assessed through peer review in a manner similar to interrater reliability. Ongoing peer review was used to provide an external review of the overall research process. Research team members, women with disabilities, and an outside consultant reviewed the recruitment handbook, methods, and moderator guides prior to implementation of the study. Selected members of the research team, trusted colleagues, and the principal investigator's

primary advisor who did not have a direct role in the research project provided advice and support during the analysis.

Finally, rich, thick descriptions have been used throughout the following chapters to enable the reader to make decisions regarding the transferability of findings (Creswell, 1998). These descriptions will help readers reach their own conclusions, make their own interpretations and determine for themselves whether the findings from this study can be transferred to other settings.

Researcher Bias and Assumptions

In all qualitative research, the researcher is the primary instrument for data collection and analyses and therefore must be aware of any personal biases that may influence the investigation (Merriam, 1998). The following assumptions have influenced the reliability and validity of this study. First, disability is socially constructed. It results from the interaction of a person with the environment. Second, women with disabilities can live long healthy lives and should have access to the full range of preventive health services. Third, mammography screening is the best way to detect breast cancer early when it is easiest to treat. And finally, the public health community has not adequately addressed breast cancer screening among women with disabilities. Previous interactions with women with disabilities and personal experiences (both positive and negative) obtaining preventive health care have also influenced the interpretation of findings. Therefore, the final analyses consist of descriptive accounts of disabled women's experiences with breast cancer screening that are filtered through the principal investigator's own perceptions, experiences and interpretations.

Data Handling and Analyses

Transcription Process - The focus group discussions were captured word for word using a certified court stenographer. The cost of this service was approximately \$1,000 per transcript. As back up, each focus group was audiotaped in its entirety. The resulting transcripts were reviewed for accuracy by the principal investigator. No identifying information was included in the transcripts. Only fictitious names were used during the focus group sessions. All audio cassettes from the focus groups will be destroyed at the completion of the study.

Software/Data Management – Qualitative data from the transcriptions were converted into text files for analyses using QSR NUD*IST Version 6, also referred to as N6. NUD*IST stands for Non-numerical Unstructured Data * Indexing Searching and Theorizing. This computer software program was specifically designed to code, classify, and index non-numerical, unstructured text typically used in qualitative research. The software was developed in 1991 and is supported by QSR International Pty Ltd in Australia and is considered by many to be one of the leading software packages used in qualitative research.

After importing the raw files, all the documents were subdivided into text units (the smallest segment of text the software can code and retrieve). For this analysis, the text unit preference was set for a line. Sub-headers were then used to divide the transcripts into meaningful sections.

Tree Nodes and Cataloguing- N6 provides an Index System to help researchers locate and store categories of data. This system is comprised of “nodes.” Nodes are the containers or building blocks for thinking about the data. Nodes can be organized hierarchically, in a “tree” of categories and subcategories to help organize data, clarify concepts, and explore ideas emerging from the project. These subcategories are often referred to as “children.” Prior to coding, the

principal investigator constructed a hierarchical index system based on information gleaned from reading the transcripts (See Appendix F). This index system was shared with selected members of the research team and modified based on team input. Changes to the index system, such as the addition of new subcategories, were made as coding proceeded.

Data Entry and Coding – The principal investigator read each transcript at least once, highlighted (in color) interesting passages, coded the passage, and entered the code in the margin of each transcript. In some instances, the passage was coded in more than one place. Coding was generally limited to two hours at a time to reduce investigator errors. The principal investigator reread each code prior to data entry. The principal investigator taught a fellow in the NCBDDD how to enter the codes into the N6 database. After the codes were entered, the principal investigator selected a proportion of pages from the transcripts (~10%) and rechecked the codes for accuracy. Initial thoughts and insights about the document were attached to selected nodes and stored as memos. It took the principal investigator an average of 18 hours to complete the coding for each transcript. Initial plans called for coding and coder reliability checks by at least two members of the research team. Although this would have increased the rigor of the study, it was not possible given the time, level of effort, technical expertise, and significant financial commitment that would have been required for this additional coding.

Data Analysis - There does not appear to be a consensus among researchers as to the best way to analyze qualitative data, however, constant comparative methods developed by Glaser and Strauss (1967) have increasingly been adopted by many qualitative researchers. Constant comparative methods as outlined by Miles and Huberman (1994) were used as the analytic framework for this study. The basis strategy consists of comparing one piece of data from the focus group interviews to another piece of data. The findings were derived inductively through

the use of these methods. Data analysis consisted of three concurrent activities: data reduction, data display, and conclusion drawing/verification. First, data reduction was used to select, simplify, and transform the data from the existing focus group transcripts. These data were then organized in a way that permitted describing, classifying, and identifying major themes or categories. Guidelines suggested by Merriam (1998) were used to determine the efficacy of the categories derived from the constant comparative methods. Finally, conclusion drawing and verification were used to note patterns and interpret meanings that emerged from the data.

Data Storage and Disposition – All individual information was regarded as confidential and was made available only to authorized users. A number of measures were taken to ensure the confidentiality of data. First, the screening questionnaires included a confidential code number to ensure anonymity. Second, during the focus groups, participants were asked to pick a name other than their own to be called by. Third, the data were stored in locked file cabinets and only members of the CDC research team were allowed access. The consent forms and personal identifiers were kept in a locked file cabinet in the two co-principal investigators' offices at Baylor and Kansas. Each co-investigator was responsible for half of the sites. The principal investigator did not have access to personal identifiers. Fourth, the audiotapes are currently stored in a locked cabinet in the office of the principal investigator until the study is completed, at which time they will be destroyed. All coded questionnaires, transcripts, and field notes are also kept in a locked file cabinet in the principal investigator's office at CDC. Finally, the information from all the focus groups have been combined for analysis and cannot be linked to a particular individual or focus group location.

Human Subjects Protection

Four Institutional Review Board Clearances (IRB) and two hospital research reviews were required for this study. IRB approval was simultaneously sought from the Centers for Disease Control and Prevention (CDC), the Center for Research on Women with Disabilities (CROWD), Baylor College of Medicine, the Research and Training Center on Independent Living, University of Kansas, and the University of Georgia. Each of these Institutions had a multiple project assurance from the Office for Protection from Research Risks (OPRR). In addition, the research boards at Craig Hospital and Alta Bates Medical Center reviewed all protocols. Only the CDC IRB raised issues that needed to be addressed by the research team. The revisions were addressed and summarized and sent to the co-investigators who forwarded the recommended changes and revised protocol to their Institutional Review Boards for approval. The entire process took approximately 12 weeks. (See Appendix G).

Only women meeting the eligibility criteria were allowed to participate. Written consent forms were explained verbally, followed by questions to ensure that the information was clear and understandable. For ease of reading, consent forms were written at a 7th grade reading level and made available in large print.

The potential risks associated with the intervention were minimal. However, this was an open discussion and the issues discussed could make participants uneasy. At the conclusion of each focus group, print information on breast cancer was disseminated and local referrals were made where appropriate. In Mississippi, a breast cancer expert was available to answer any questions or concerns participants might have. Any potential discomfort and inconvenience experienced by the participants was outweighed by the potential benefit of designing

interventions to reduce mortality associated with breast cancer by increasing mammography screening among women with disabilities.

CHAPTER IV

RESULTS

This chapter begins with a summary of selected participant characteristics and is followed by an overview of relevant findings. The findings were derived inductively through the use of the constant comparative method. With the exception of participant characteristics, only data addressing barriers to screening derived from groups A (never received a mammogram or had not received a mammogram within the recommended guidelines [>2 years]) and B (received a mammogram within the recommended guidelines [≤ 2 years]) will be presented. Although data describing the experiences of women with disabilities who had been diagnosed and treated for breast cancer were collected (Group C), they were significantly rich to warrant an independent analysis.

Participants

Fifty-two women with physical disabilities participated in the study as illustrated in Table 4. The mean age of participants was 53.5 years ($SD = 8.03$, range 40-77). Almost 73% of the sample was White, 22% Black, 4% Native American, and 2% Asian Pacific Islanders. Despite efforts to recruit a diverse group of participants, no Hispanic women volunteered for the study.

Focus group participants reported a variety of primary disabling conditions. The most frequently reported conditions were spinal cord injury (22%), joint and connective tissue disease such as arthritis (15.5%), cerebral palsy (10.3%), multiple sclerosis (8.6%), and polio/post-polio (8.6%). The average length of time participants had their disability was 32 years ($SD = 16.87$). Participants reported using 96 pieces of special equipment as illustrated in Table 5.

Table 4.

Participants by Selected Characteristics

	Group A N=4 groups	Group B N=4 groups	Group C N=3 groups	Total N=11 groups
Number of Participants	N=10*	N=31	N=11	N=52*
Age				
40-49	3 (33%)	12 (39%)		15 (29%)
50-59	6 (67%)	12 (39%)	6 (55%)	24 (47%)
60-69		7 (23%)	4 (36%)	11 (22%)
70-79			1 (9%)	1 (2%)
Race/Ethnicity				
Native American		2 (6%)		2 (4%)
Asian/Pacific Islander			1 (9%)	1 (2%)
Black, Non-Hispanic	4 (44%)	4 (13%)	3 (27%)	11 (22%)
Black, Hispanic				
White, Non-Hispanic	5 (56%)	25 (81%)	7 (64%)	37 (73%)
White, Hispanic				
Primary Disabling Condition(s)	N=10	N=35	N=13	N=58
Spinal Cord Injury	2 (20%)	10 (29%)	1 (8%)	13 (22%)
Joint & Connective Tissue Disease (Lupus, Arthritis, Scleroderma)	2 (20%)	4 (11%)	3 (23%)	9 (16%)
Cerebral Palsy		3 (9%)	3 (23%)	6 (10%)
Multiple Sclerosis	1 (10%)	3 (9%)	1 (8%)	5 (9%)
Polio/post-polio		1 (3%)	4 (31%)	5 (9%)
Muscular Dystrophy	2 (20%)	2 (6%)		4 (7%)
Traumatic Brain Injury		2 (6%)		2 (3%)
Stroke		2 (6%)		2 (3%)
Spina Bifida		1 (3%)		1 (2%)
Amputation		1 (3%)		1 (2%)
Other (back problems, nerve damage, Fredricks ataxia, hemiparalysis, paraplegia, Chariot-Marie-Tooth Syndrome)	3 (30%)	6 (17%)	1 (8%)	10 (17%)

Length of Time Since Last Mammogram				
≤ 2 years		31 (100%)	10 (91%)	41 (80%)
> 2 years	6 (67%)			6 (12%)
Don't Know	3 (33%)		1 (9%)	4 (8%)

* Missing demographic data from one participant.

Table 5

Group by Special Equipment

	Group A N=4 groups	Group B N=4 groups	Group C N=3 groups	Total N=11 groups
Number of Participants	N=10*	N=31	N=11	N=52*
Number of Special Equipment	N= 17	N=59	N=20	N=96
Types of Equipment				
Power Wheelchair	4 (24%)	11 (19%)	8 (40%)	23 (24%)
Manual Wheelchair	4 (24%)	15 (25%)	2 (10%)	21 (22%)
Cane	3 (18%)	7 (12%)	5 (25%)	15 (16%)
Braces or other orthotic devices	2 (12%)	5 (8%)	1 (5%)	8 (8%)
Walker	1 (6%)	6 (10%)		7 (7%)
3-Wheeled Cart	1 (6%)	4 (7%)	1 (5%)	6 (6%)
Hospital Bed	2 (12%)	3 (5%)		5 (5%)
Crutches		1 (2%)	1 (5%)	2 (2%)
Ventilator			1 (5%)	1 (1%)
Other (Scooter, Lift, Hearing Aide, Service Dog, Bath Bench, Communication Board)		7 (12%)	1 (5%)	8 (8%)

* Missing data from one participant.

The most frequently reported assistive devices included power wheelchairs (24%), manual wheelchairs (22%), canes (16%), and braces and other orthotic devices (8%).

Ten women (19.2%) were assigned to Group A (never received a mammogram or had not received a mammogram within the recommended guidelines [>2 years]). Thirty-one women

(59.6%) were assigned to Group B (received a mammogram within the recommended guidelines [≤ 2 years]). Eleven women (21.2%) were assigned to Group C (survived breast cancer). Eighty percent of all participants (Groups B+C) had received a mammogram within the recommended guidelines (<2 years).

Categories and Properties

Cultural values, health beliefs, attitudes, and the physical environment have been shown to affect health-screening behaviors in the general population. Findings from this study suggest that several unique physical and attitudinal barriers may contribute to a lack of screening among women with physical disabilities. Data analyses revealed that these barriers generally fell into three categories: 1) attitudinal barriers, 2) environmental barriers, and 3) system-level barriers. These categories and their associated properties are displayed in Table 6.

Table 6.

Categories and Properties

Categories and Properties
Barriers to Breast Cancer Screening
I. Attitudinal Barriers
Participants' attitudes and beliefs
Providers' attitudes and beliefs
II. Environmental Barriers
Physical
Social
III. System Barriers
Financial
Educational
Communication

Attitudinal Barriers

A variety of attitudinal barriers that impact breast cancer screening among women with physical disabilities were identified and discussed in each of the eight focus groups. These barriers typically fell into two sub-categories, participants' attitudes and beliefs, and providers' attitudes and beliefs.

Participants' Attitudes & Beliefs

Women with disabilities across all eight focus groups understood the purpose of breast cancer screening and the differences between clinical breast examinations, breast self-exams, and mammography screening. Most participants agreed that mammography was the best way to detect breast cancer early, when it was easiest to treat. Typical comments supporting this statement were, "All my life I've been hearing that cancer is best treated when it is caught early," and "I think it (mammography screening) has proven to be the best way, because so many people have found that they have breast cancer that would have never found it from a manual exam." Mammography screening was the primary method of detecting breast cancer for some women with physical disabilities who, because of their disability, had difficulty with manual dexterity. As one participant noted, "I can't feel anything so a mammogram is my only, my best option." Several participants commented that early detection saved lives. One woman stated, "I've heard other people say that they caught it early, you know, through a mammogram, and that their life was saved because the cancer didn't develop, didn't spread."

Although the majority of participants believed that mammography was the best way to detect breast cancer, participants in five of the eight groups felt that breast self-examination was the best way to detect breast cancer early. As one woman remarked, "I think the self-exams are probably the best way; the quickest, the most easily detected because a woman knows her body."

Participants in two of the A groups did not believe that mammograms were efficacious. One woman commented “What’s the purpose of having a mammogram if it’s not 100 percent? We’re having expensive mammograms every year and nothing shows up, but that still doesn’t mean that we don’t have the cancer.” Although an outlier, one participant believed that mammography was a way to “keep all those technicians, distributors, and manufacturers of that equipment, and those doctors in business.”

Surprisingly, many women in this study could not accurately identify known risk factors for breast cancer. Across all the groups, participants mentioned 18 different risk factors for Table 7.

Group by Risk Factors

	Group A N=4 groups	Group B N=4 groups	Total N=8
Established Risk Factors			
Age	3	3	6
Family History	4	4	8
Race	2	1	3
Obesity	1	2	3
Nulliparity	0	1	1
Associated Risk Factors			
Oral Contraceptives	1	1	2
Estrogen/ Hormones	0	2	2
Perceived Risk Factors			
Smoking	1	3	4
Caffeine	1	1	2
Abuse	1	0	1
High Cholesterol	1	0	1
High Blood Pressure	1	0	1
Diabetes	1	0	1
Exercise	0	2	2
Supplements	0	2	2
Diet	0	1	1
Stroke	0	1	1
Environment	0	1	1

breast cancer, of which only five (family history, age, race, obesity, and nulliparity) were actual established risk factors. All eight groups understood the link between family history of breast cancer and increased risk. Six of the eight groups recognized that age was also a leading risk factor for breast cancer. Even so, some participants were unsure at what age they should be screened. For example, one woman noted, “I think as you age, it might be that you have to go more than if you was a younger person, but I’m not too sure.” Only three groups discussed either race or obesity as known risk factors for breast cancer. Interestingly, women could identify race as a risk factor but their knowledge and understanding of the risk was inaccurate. Typical comments were “We (African American women) have more breast cancer than Whites” and “I’ve heard, in the back of my mind, that women of color seem to have a higher risk for breast cancer.” There was also some confusion about weight. One participant stated, “I’ve heard things if you are overweight, you are at higher risk, and if you are underweight you are at higher risk. I don’t know.” Of the established risk factors that were mentioned, only one participant in a B group understood the link between never having children and breast cancer.

Recognized associations between breast cancer and the use of oral contraceptives were barely mentioned by two groups, an A group and a B group. The association between menopausal estrogens and breast cancer, which should be a concern for disabled women in this age group, was minimally discussed in only two of the B groups.

Lack of awareness about the risk factors for breast cancer was evident. Although it has numerous health risks, half of the groups incorrectly identified smoking as a major risk factor for breast cancer. Two groups, an A group and a B group, each mentioned coffee or “too much caffeine” as possible risk factors. In addition, women assigned to group A inaccurately believed that physical abuse, high cholesterol, high blood pressure, and diabetes were also risk factors for

breast cancer. One woman thought “that if they have a relation with somebody that always beats on them” they were at increased risk for breast cancer. Inaccurate risk factors identified by group B participants included exercise, use of supplements, diet, stroke, and the environment. Two groups mentioned that exercise or participating in “rough sports where you are likely to get a lot of bruises on your breast area” might also put you at increased risk for breast cancer.

An often-unrecognized barrier to screening among disabled women was their lack of perceived susceptibility. Some participants did not think they could get breast cancer. The concept that “lightening doesn’t strike twice” emerged in three of the focus groups. As one woman commented, “God gave me this disability, he wouldn’t give me breast cancer too.” Another woman noted, “You think because you’re in a chair that nothing else bad is going to happen to you.”

A few participants completely disregarded their risk of getting breast cancer because they did not have a family member with it. Yet, when asked if they personally knew someone with breast cancer, almost everyone could identify someone who had it. Across all the groups participants identified mothers, grandmothers, aunts, cousins, friends, neighbors and coworkers who had battled breast cancer. Women who had a close family member with breast cancer were likely to be screened regularly. As one participant commented, “My mother had breast cancer. She had a left breast taken off all the way down to the bone under her arm. And she had it a long time before she knew it. But, you know, I remember how it looks. And so I don’t take any chances, I try to go once a year.”

When asked if breast cancer is something they personally worry about, quite a few participants commented that breast cancer is not something they usually think about. In five of the eight groups, several women stated that they would rather not know if they had breast cancer.

Typical comments were “I prefer not knowing,” and “As long as I don’t know it, then I’m okay.” Many women indicated that they couldn’t possibly handle their disabling condition and cancer too, so they were “better off not knowing.” One participant noted, “I already have disabilities and I’m afraid, if I go and get a screening, they might say that I have it, so then that’s something else I have to worry about.” Another woman commented, “That’s just another problem that’s going to hit me in the face, and I don’t want to face it.”

Many women believed that if they were predestined to get cancer there was nothing that could be done to prevent it. Several women commented, “If I’ve got it, it was meant to be,” “You can’t worry over things you don’t have any control over,” and “If I’m going to get it, I’m going to get it. Why should I get screened for it?”

Pre-occupation with disability-related health issues was another commonly identified barrier to screening discussed by five of the eight groups. One woman commented “I’ve got my disability already. That is living hell. Why do I even want to find out if I have something else wrong with me?” Participants across these groups were more likely to worry about their existing health problems than breast cancer. One woman who has multiple sclerosis (MS) stated “It’s on the back burner right now because I’m just so involved with the pain of this disease.” Other typical comments included “I’ve got too many other things to worry about,” and “It’s just not high on my priority list—everything else gets in the way.” One participant summed it up by noting, “Women with disabilities have so many problems with their disabling conditions, that they have to take care of, that these other maintenance-type things fall by the wayside.”

When asked about prior experiences with mammography, participants across seven of the focus groups (all 4 A groups and 3 of the B groups) commented about the pain or discomfort they experienced during the procedure. Typical comments from women who had not been

screened in more than two years were “The machine, it hurts you too much,” “My last experience was so painful, I haven’t been back,” and “I’m just not in a hurry to have another one anytime soon.” Women who had been screened within the recommended guidelines had similar comments. One woman noted, “They’re pulling it up and pulling it forward and killing me, and I hate them.” Another woman who was hypersensitive due to her disabling condition commented, “If I put my body up against something ice cold, it’s going to feel like a knife stabbing in me. Well, a normal person will just feel very cold and uncomfortable. It’s going to hurt me.” On the other hand, some women in the B groups commented that the experience, while at times might be uncomfortable, wasn’t always painful. One woman noted “I didn’t have any problem with it this last time and all the other times, it hurt a lot.” Another participant remarked, “I have had tests that were much more difficult to go through, and on a scale of 1 to 10, with 10 being the most difficult, I would say a mammogram is about 2.” A few women noted that the amount of discomfort they experienced may have been related to the technician’s care, skill, and training.

In three of the eight focus groups women identified embarrassment as an important barrier to breast cancer screening for women with disabilities. One woman noted, “Maybe it’s part of my problem, but it’s embarrassing.” Another stated, “It’s a terribly humiliating thing to go through.” A different participant commented, “You have to get naked and do it sitting down if you’re in a chair. They always need to call someone in to help and, until you get used to being touched, you know, that way, and then it hurts. It’s an intimidating kind of test.”

Providers’ Attitudes & Beliefs

Provider attitudes, beliefs, and assumptions may influence breast cancer screening among women with physical disabilities. Participants described experiences with health care providers ranging from caring and knowledgeable to encounters with providers who were insensitive to

disability issues. One woman remarked, “I just think that sometimes people are not sensitive to people that have a disability.” Another commented, “There are doctors who don’t want us as patients.” One participant noted, “I feel that a lot of times, people with disabilities put off going to see the doctor because of the way the nurses or the receptionists treats them.” According to participants, many health care providers lack a basic understanding of disability and some providers are uncomfortably interacting with a person with a disability. One woman commented, “They look at me and I could even hear whispering, what do we do with her, what do we do with her. They don’t understand cerebral palsy, and they don’t understand how I move and what I do.”

The attitudes and perceptions of health care providers were discussed by six of the eight groups. According to some participants, providers frequently made inaccurate assumptions about intelligence based on their perceptions of disability. It was not uncommon for women with physical disabilities to be treated as if they had mental retardation. One woman commented, “Sometimes they assume because I wrinkle my eyes at them that I don’t know anything and they assume that I’m retarded.” Another participant stated, “None of us in this room is stupid. I mean, we’re all average or above intelligence. And just because we’ve got a disability doesn’t mean that I’m mental or my acumen has been challenged in any way.” Other participants expressed anger about the way they have been treated. One woman remarked, “They may be slow in talking or they may say a word just a bit differently or they may drool as I do. But at the same time, they can still use that brain, and they are not dumb. And sometimes we’re treated in that respect. And that just humiliates me and makes me very angry.”

Environmental Barriers

Participants discussed a variety of environmental barriers (e.g., transportation, inaccessible facilities and equipment, personal assistance, and difficulty with positioning) that may impact breast cancer screening among women with disabilities. These environmental barriers can be sub-divided conceptually into two categories, physical and social. Physical barriers such as transportation or inaccessible facilities and equipment are products of the built environment. Social barriers such as the lack of personal assistance reflect the restrictions society places on individuals that limits their ability to participate independently in tasks, activities or roles.

Physical Barriers

Although transportation was a frequently mentioned barrier to screening, it was not the availability of transportation that was the problem; it was the reliability of the service and lack of assistance that seemed to create the barrier. Participants reported being called the night before and being told that their transportation had been canceled. Others discussed the problems with drivers. Even if transportation was available, many women with disabilities needed help getting in and out of the van. According to one participant, “drivers don’t really assist a person when they go pick them up, often they tell you it’s not in their job description.” One woman commented, “If Medicaid is going to pay someone to pick up someone, the driver should be able to help that person.”

For women who were fortunate to have their own transportation, lack of accessible parking frequently created major obstacles. Participants in three of the four B groups commented that the numbers of accessible parking spaces that do exist are often full or poorly placed. Typical comments were “I have a van with a lift, and there is really no accessible

parking,” or “they have handicapped parking spaces but they’re usually full.” The location of the parking elicited a lot of discussion. One group mentioned the wheeling distance from the parking lot to the screening site as a barrier. Another woman stated, “What kills me about my gynecologist’s office, it’s a real, real fancy office, with a drive under where you won’t get wet. But that’s not where the ramp is. That’s where the steps are. The ramp and the place for handicapped is around the back, and there is no cover.” This is especially difficult for disabled women who discussed having had to cancel screening appointments due to bad weather.

As expected, the majority of the groups discussed the lack of accessible screening sites. A typical comment was “They don’t know what accessible is.” One woman remarked, “There are still to this day some places that are not accessible. Oddly enough, I find it amazing.” One group A participant commented, “My whole reason, I guess, for not having a mammogram is the physical end of it.” Numerous complaints were voiced about inaccessible ramps, doors, rest rooms, dressing rooms, examination rooms, and equipment. Opening doors created a significant problem for women with limited upper body strength. Inaccessible equipment was discussed in seven of the eight groups, and room size in another four groups. Many participants discussed the inflexibility of the mammography equipment and their inability to maneuver their chair close enough to the machine. Several participants commented on the need for equipment that can be “adjusted or lowered” to accommodate women with disabilities. Participants felt that these access issues must be addressed by the health care system. As one woman stated, “Every doctor, sooner or later, is going to have some patient come in to see him with a disability.”

Social Barriers

Several women identified the lack of personal assistance (e.g., filling out forms, transferring, dressing, balancing, or standing) as a major barrier to breast cancer screening. One

participant who went for screening was actually told that if she wanted assistance it was up to her to bring someone with her. One woman, who had trouble with motor coordination, stated, “I’ll just ask ahead of time, will someone be available to help me fill out the paperwork? And they say, well, no. It’s not that much. You can probably do it. I said no, trust me, you wouldn’t be able to read it if I tried to do it.”

A number of women were told that clinic staff were too busy to help and they would need to be rescheduled. This may prove to be difficult for many women with disabilities who require an enormous amount of planning and coordination to get to their scheduled appointments. As one participant remarked, “I plan a week ahead to get my ride there and stuff. I show up and they say, oh, we have to change your appointment till tomorrow. I’m like no; I’ll wait all day if I have to. You’ll get me in today. Then they get a little annoyed. But I’ll sit there all day until they get me in. Because I’m not going to go through that again to show up tomorrow.” Some women have chosen not to return because of problems with personal assistance. One participant remarked, “I went and they said, we don’t have time to help you. I asked for help because I need it, not because I wanted it. And they said, well, we’ll have to reschedule you because we don’t have time today. And I was there an hour before my appointment to give them time to help me. So I said fine, well, cancel the appointment and I won’t be coming back.”

One B group spent a considerable amount of time discussing problems associated with getting in and out of the dressing gowns. One woman stated, “Tell me how a one-handed person can get in a three-armed thing—and then let alone to tie it when you only have one hand. It’s disgusting.” Another participant commented, “They might as well have you come out naked, because by the time I get the gown on and I’m wheeling, it’s falling down anyway because they’re so big.”

Five of the eight groups discussed safety and the need for personal assistance with standing. As one participant noted, “When I went to have the mammogram, they asked me if I could stand. I told them I could stand for just a few minutes. And I said you’re going to have to hold me. And the lady was holding me, but then she turned me loose.” Participants voiced concerns about safety. One woman stated, “Other people don’t understand the balance issues. They lean you too far and you are gone.” Another participant commented, “I’m very unstable standing on my feet, and they’ll say move over this way, move over. I feel like I’m falling on the floor, and I’m very protective about not falling on the floor because I’ve done it a few times, it’s not that comfortable.”

Being able to get into the proper position for a mammogram was an important concern that was raised in seven of the eight focus groups. Women discussed experiences where technicians used pillows, and in one instance a phone book, to position them properly. One woman commented, “They prop you and it hurts. I have trouble sitting and they prop you up with pillows to get you in the right position.” Another woman commented, “The ability to situate yourself to the point where they can get a good, clear mammogram. It’s difficult. I sometimes wonder if the mammograms that I have had have been really all that helpful because I can’t get up to the machine as close as I’ve seen other people do. And is it really, you know worth it, the time and resources and everything else? I don’t know.”

System Barriers

Participants identified three types of system-level barriers that impact breast cancer screening among women with disabilities: financial barriers, educational barriers, and communication barriers.

Financial

The costs associated with breast cancer screening were discussed in seven of the eight focus groups. Although the cost of screening was not a significant barrier for study participants, several women suggested that it might be a barrier for other disabled women since many women with disabilities have low incomes and are underinsured. Typical comments were “There are many people that don’t have health insurance,” and “It isn’t high on their priority list if they know they can’t afford it.” One participant noted, “Most people who have disabilities are on a fixed income and a lot of women don’t have these procedures done because they’re afraid that the insurance will only pay part of it and they will be obligated to pay the rest of it. So they choose not to have it done because they just can’t, some of us can’t afford it.”

Educational

Several women expressed frustration with the lack of provider training and education. Women were amazed that clinic staff did not understand basic disability terminology. One participant shared the following story:

“I’m just amazed sometimes that physicians and caretakers, nurses and so forth do not seem to have any concept of mobility problems. When I had my daughter, I had a section. Afterwards, the nurse comes in and says that I need to get up, that Dr. XXXX likes for his c-section patients to start walking first thing the next morning. And I said, glory, glory, I would have had a child lots sooner if I knew I was going to be able to walk. And she just looked at me like I was crazy, you know. And I said, I’m a paraplegic. And she still looked at me like, well, you know. I said that means I can’t walk, my legs don’t move. And she literally said to me, the doctor insists that his patients walk. I don’t understand. Do they not teach this?”

Given the apparent lack of disability training in medical school, some women with disabilities felt it was their responsibility to train medical providers. One woman commented, “I think as frustrating as it is to be asked questions like, can you just stand up or there’s only one step or something like that. You just have to accept it. These people are ignorant about that. And I have taken it as my job instead of getting angry like I initially did, it’s my job to educate them.” Other participants have grown tired of educating providers as one woman noted, “To have to go through and explain it over and over and over—I’m so tired of teaching people. This is not my job. My job is to live my life. Your job is to be a health care provider.”

Women with disabilities may be less likely than women without disabilities to be given a physician referral for a mammogram. One participant commented, “Why aren’t doctors asking, you know, have you had your mammogram or have you had your other exams? I think the doctors should encourage their patients. Because if you’re their general doctor, you should be interested in their general health.” Typical comments included, “He hasn’t reminded me that I need to get it done,” “He is just too busy to be bothered,” and “It’s hard, let’s not do it this time.” One 48-year-old woman stated, “I asked the doctor, myself, did I need to have a mammogram. He said, oh, no. He felt that a manual exam was enough, that I didn’t have to fool with going through that.” Another woman commented, “My family doctor told me I did not need Pap smears anymore, and I knew it was because he didn’t want or couldn’t get me up on his table. So this is his way of handling it.” Conversely, several group B participants reported having a mammogram because their physician recommended it.

Communication

Communication between women with disabilities and their providers emerged as a problem experienced by several women. According to participants, providers may not know how

to communicate with women with disabilities, often talking to a family member or a personal assistant rather than the woman herself. As one woman noted, “I’ve gone to the doctor’s office with my 78-year-old mother, and they would address her, and I’m the one standing there. And I said, I can take care of this. I can answer those questions. But they immediately think because I have that walker, that something is wrong, that I’m not intelligent enough to answer their simple questions. Or they will ask her, can she do this—and I’m sitting there.”

Lack of information about where to go for free or accessible screening were frequently cited barriers. The majority of participants had never heard of the National Breast and Cervical Cancer Screening Program, a CDC sponsored program that offers free mammograms to underserved women in every State. The women who had heard of it were not sure what the program had to offer, particularly for women with disabilities. Additionally, in each focus group there were individuals who were unaware that accessible equipment existed that could facilitate screening. Typical comments were “I didn’t know they had anything like that,” and “It never dawned on me that they could do it in any position other than standing.” One woman remarked, “Until just a few months ago I never knew that a person could have a mammogram while sitting down in a chair.” If they were aware that accessible screening existed, many women with disabilities did not know where to find it. As one participant concluded, “If you don’t know it’s there, it doesn’t help you.”

During the focus groups women with disabilities noted the lack of health promotion materials targeting women with disabilities. We frequently heard, “you never see disabled women in any of the existing materials.” Participants felt that this was something that should be addressed by the public health community.

In summary, participants identified a variety of barriers that impact breast cancer screening among women with physical disabilities. These barriers typically fell into three overarching categories: 1) attitudinal barriers, 2) environmental barriers, and 3) system-level barriers. Combined, these barriers may have a considerable effect on mammography screening for this underserved population of women.

CHAPTER V

DISCUSSION

Cultural values, health beliefs, attitudes, and the physical environment have been shown to affect screening behaviors in the general population. Among non-disabled women, concerns about radiation, pain, cost, access, lack of perceived susceptibility, and lack of physician referral have been associated with lower rates of mammography utilization (HHS, 2000; Rimer, 1995). Results from this study are consistent with those reported in the literature. In addition to these typical concerns, findings from this study suggest that several unique barriers may contribute to a lack of breast cancer screening among women with physical disabilities.

Results from this study suggest that barriers to screening generally fall into three categories: 1) environmental barriers, 2) attitudinal barriers, and 3) system-level barriers. To eliminate the barriers to breast cancer screening for women with physical disabilities, all three of these must be addressed. Improving screening rates will require a multifaceted approach at the federal, state, and local level focused on improving environmental access, enhancing provider training and education, increasing outreach efforts to women with disabilities, and improving health communication.

Environmental Access

For many women with physical disabilities, obtaining regular breast cancer screenings can be challenging. The majority of women in this study described substantial difficulties with screening resulting from numerous physical and social barriers. Findings from this research suggest that women with disabilities may experience difficulty with reliable transportation,

parking, getting into the doctor's office, undressing for an exam, and standing, or positioning during a mammogram. Personal assistance, although frequently needed, was rarely available. These environmental barriers are comparable to those reported in the disability literature by Becker, Stuijbergen and Tinkle (1997) and Nosek and Howland (1997).

Many of these environmental barriers can be easily eliminated. For example, health care facilities should make sure that a sufficient number of accessible parking spaces are available close to building entrances. All interior and exterior doors should be wide and easy to open. The path through the facility and service areas should be clear and easily accessible to a woman using a wheelchair or other assistive devices. Restrooms and dressing rooms should be large enough for a person using a wheelchair to navigate. Equipment such as motorized, adjustable-height treatment and examining tables and chairs should be available in all medical facilities. And personal assistance should be available to help women with dressing, transferring, and positioning when requested.

Resources are available that can help providers eliminate physical barriers. *Removing Barriers to Health Care*, produced by the Center for Universal Design at North Carolina State University and the North Carolina Office on Disability and Health is an excellent resource on how to make healthcare facilities more universally accessible (see www.fpg.unc.edu/~ncodh/). More recently, Massachusetts has dedicated staff and resources to improving the accessibility of mammography facilities throughout the state. With support from the CDC, health department personnel have just developed a survey instrument to help mammography facilities assess the core elements of physical access. The results of these surveys will be disseminated statewide, providing, for the first time, accurate information on where women with disabilities can go for accessible screening.

Comprehensive programs are being developed to help women with disabilities overcome these environmental barriers to breast cancer screening. The Breast Health Access for Women with Disabilities (BHAWD) program located at the Alta Bates Summit Medical Center in Berkeley, California is one example. This community-based program provides free clinical breast examinations, breast self-examination education, and referrals to accessible mammography sites to women aged 20 and older who experience barriers to breast healthcare due to their disabilities. In this program, a nurse specialist provides free clinical breast exams and breast self-exam education to women with disabilities. Exam rooms are fully accessible, with attendants available to help transfer patients to a multi-positioning exam table. Women are referred to mammography services that can accommodate women who use wheelchairs or have difficulty standing. The medical staff are trained to be sensitive to disability issues, and staff will coordinate accessible transportation for those women who need it. The program has also developed techniques to teach women with limited hand functionality to perform breast self-exams.

Provider Training and Education

Attitudes on the part of healthcare professionals can present significant barriers to accessing breast cancer screening for disabled women and are often the most difficult to overcome. Healthcare providers may not recognize that women with disabilities can benefit from the full range of preventive health care services and therefore may not recommend breast cancer screening for their patients. Some providers may have the false impression that disabled women are asexual and do not need regular preventive services such as breast or cervical cancer screening or they may think that it is impossible to perform a comprehensive examination

because of the woman's disability. Due to the increasing costs of healthcare delivery, these providers may be reluctant to spend the extra time needed to perform a complete exam.

Many healthcare providers have not been adequately trained to address problems and issues related to disability. As suggested in this study, women with disabilities often state that they spend considerable time educating their health care providers about their disability. Reports from people with disabilities suggest that providers often focus on their disabling condition rather than the health issue that was the reason for their visit. Healthcare providers and their office staff need to have training on the basic rules of disability etiquette and how to best communicate with and assist women with disabilities. For example, if you offer assistance to a woman with a disability, wait to see if your offer is accepted and listen to any instructions about the best way to help. Do not touch a person's wheelchair or other assistive devices without permission. And speak directly to the woman with a disability, not the person who may be accompanying her to the appointment.

One reason for this lack of awareness may be insufficient medical training. Few medical schools include information on the health needs of women with disabilities in their standard curriculum. Providers of screening services must be educated about the special healthcare needs of women with disabilities, taught techniques for conducting mammograms and other clinical procedures that accommodate disabled women, and trained in managing disability-related symptoms that may interfere with screening.

Another issue that may contribute to this lack of sensitivity may be related to how providers view disability with respect to themselves. Healthcare providers are knowledgeable enough to understand that disability can medically impact a person's life and it may remind them

of their own vulnerability. They have not been taught that disability is not synonymous with poor health and that people with disabilities can live long, healthy, and fulfilling lives.

Resources and materials are available to assist health professionals in implementing screening programs for disabled women. For example, *Breast Health and Beyond for Women with Disabilities: A Guide to the Examination and Screening of Women with Disabilities*, released in November, 2003 by BHAWD, was developed to increase provider knowledge and awareness in providing clinical breast cancer screening services to women with disabilities. The guide includes information on disability awareness, universal design, accessible equipment, positioning, and specific protocols for clinical breast examination (CBE), breast self-exam (BSE) and mammography.

Reproductive Health for Women with SCI: The Gynecological Examination is a training video for healthcare providers developed at and available through the University of Alabama at Birmingham. The video helps to educate clinicians on how to safely provide gynecological examinations to women with spinal cord injuries. Covered in the video are autonomic dysreflexia management, wheelchair to examination table transfer, patient positioning on the examination table, clinical breast examination, mammograms, and Pap tests.

Provider training and education is a critical factor in improving screening services for women with disabilities. *Count Us In* is a health promotion program developed by Duke University Medical Center and the North Carolina Office on Disability and Health. This CDC funded demonstration project was designed to increase breast and cervical cancer screening among women with disabilities residing in North Carolina. At the heart of the program is a training curriculum developed for nursing, physician assistant, and family medicine residency programs. To further address provider training and education, CDC is working with the

American College of Obstetricians and gynecologists (ACOG) to assess the training needs of practitioners nationwide. Understanding these training needs will lead to improved continuing education and better screening services for women with disabilities.

Outreach and Education for Women with Disabilities

Interestingly, many participants in this study did not understand that they were at risk for breast cancer. Several women were too occupied with other disability-related health issues to be concerned about cancer. One participant expressed discomfort with “being touched that way” and may not have understood what is considered acceptable touching during this medical procedure. Nosek (1996) suggests that social isolation and lack of information about sexuality may contribute to these perceptions.

Outreach and education to women with disabilities should be a critical component of any intervention to increase screening. Like all women, women with disabilities must to be made aware that they are at risk for breast cancer and given accurate information about what to expect prior to the examination. Lightning can and does strike twice. Women with disabilities may need to overcome unique physical and attitudinal barriers—or be inspired by different motivators—to adopt healthier lifestyles. To increase screening among this population of underserved women, the public health community must convince disabled women that they are at risk for breast cancer and help to elevate the importance of mammography screening on their long list of priorities.

Health Communication

Health communication is increasingly recognized as an important part of public health that can help increase awareness of potential health risks, motivate individuals to change unhealthy behaviors, and influence attitudes and beliefs (HHS, 2000). Yet, as indicated by

participants in this study, few health messages exist that target women with disabilities. To reach women with disabilities, effective health messages may require additional information such as where to find accessible screening sites or health information may need to be presented in alternative formats such as large print, Braille, or American Sign Language (ASL). In addition, women with disabilities must see themselves, not models, reflected in the messages and health promotion materials. Based on the compelling findings from this study, CDC has contracted with a national marketing firm to help them develop a health promotion campaign to increase breast cancer screening among women with disabilities.

Study Limitations

This study has several limitations. Participants were recruited from organizations (e.g., CILs, rehab hospitals, specialty clinics) that serve people with disabilities, thus introducing the possibility of selection bias. Women with disabilities who do not utilize the services of these organizations may have been less likely to participate in the study and may perceive barriers to breast cancer screening differently. The barriers described in this study may reflect the experiences of women for whom breast cancer screening was particularly important or problematic. The findings from this study are not quantitative and cannot be generalized to the population of women with disabilities. Data were only available for women with physical disabilities and may not reflect the unique barriers encountered by healthcare providers or women with cognitive disabilities or sensory impairments. Finally, given the qualitative nature of this study, researcher bias may have influenced the data analyses. Despite these constraints, the focus group interviews yielded valuable insights about the barriers to breast cancer screening among women with physical disabilities that would have been difficult to glean through other data collection techniques.

Conclusion

Women with physical disabilities are at risk for breast cancer, yet environmental (physical and social), attitudinal, and system-level barriers continue to contribute to their not getting screened. This study demonstrates that more attention should be given to breast cancer screening for women with disabilities. Particular consideration must be given to addressing environmental access, provider training and education, and consumer knowledge and beliefs. Additional research is needed to explore the barriers to screening experienced by women with cognitive disabilities and sensory impairments as these barriers may differ from those identified by women with physical disabilities.

Healthcare providers must be careful not to overlook the preventive health needs of women with disabilities. As women with disabilities live longer lives, clinicians must recognize that these women also benefit from the full range of preventive services. Efforts to improve provider training should include basic disability etiquette as well as examination techniques that can accommodate women with disabilities and any disability-related symptom that may interfere with the examination.

Breast cancer screening facilities must be made accessible to all women with disabilities. To increase the likelihood that women receive regular preventive screenings, accessible equipment such as adjustable-height examination tables and accessible mammography machines must be widely available.

Women with physical disabilities must be the target of future outreach and educational activities. New health messages must be developed that convince women with disabilities that they are at risk for breast cancer. Research to determine the most effective methods for

delivering these messages is critical and should explore the impact of the information on the target audience.

Strategies to reduce screening disparities will require multifaceted approaches that include behavioral and environmental components. Further research is needed to better understand how these cognitive and environmental barriers interact to predict breast cancer screening behaviors among this underserved population of women. Better understanding of these critical barriers will lead to improved interventions directed at reducing breast cancer mortality among women with disabilities.

CHAPTER VI

IMPLICATIONS FOR SOCIAL WORK PRACTICE

To date, social work has played a limited role in disability policy, practice, and research (Beaulaurier & Taylor, 2001; DePoy & Miller, 1996; Gourdine & Saunders, 2002; Mackelprang & Salsgiver, 1996). For over a decade articles discussing the lack of disability content in the social work curriculum can be found in the social work literature (Depoy & Miller, 1996; DeWeaver & Kropf, 1992; Gourdine & Sanders, 2002; Orlin, 1995;). The debate regarding the most effective ways of including disability training in social work education (infusion vs. field placement) has not been resolved. Although social work is required to address vulnerable populations in its curriculum, published studies raise concerns about how well social work students are being prepared to work in the disability field (DePoy & Miller, 1996; Gourdine & Saunders, 2002).

Although articles addressing social work and breast cancer have appeared in the literature (Boynton & Thyer, 1994; Cwikel & Behar, 1999), none of these articles address the important role social work could play in helping women with physical disabilities obtain breast cancer screening and treatment services. Yet, medical and public health social workers are in unique positions to influence public policy and the delivery of cancer screening and treatment services to this underserved population of women.

Social Work Training and Education

Like many healthcare providers, most social workers receive little or no training in the area of disability. Medical and public health social workers that provide direct services to

women with physical disabilities must learn the basic rules of disability etiquette and how to communicate effectively with women with disabilities. For example, when introduced to a woman with limited hand use or an artificial limb, it is appropriate to shake her hand. Social workers should remember to speak directly to the woman with the disability, not her attendant. They should never assume that a woman with a speech impairment has a cognitive disability. Social workers should also be aware that women with physical disabilities, like those in this study, may have had previous negative experiences with breast cancer screening, are fearful of pain or discomfort, and may experience high levels of anxiety associated with screening. Providing information and strategies for decreasing anxiety may reduce or eliminate this apprehension.

Resource Identification

Social workers can be instrumental in promoting and obtaining breast cancer screening services for women with disabilities. However, to be effective, medical and public health social workers will need to become aware of a different array of community-based resources such as interpreter services, accessible transportation, personal assistance services, and the location of accessible screening sites. Social workers may need to establish ongoing relationships with their local Centers for Independent Living in an effort to expand their knowledge of these disability resources. Public health social workers can also work collaboratively with these disability organizations to promote the availability of accessible screening facilities in the community and encourage disabled women to be screened.

Emotional and Social Support

Women with disabilities who are diagnosed with breast cancer are likely to have multiple needs that could be addressed by social workers. There may be an immediate need for

information about the diagnosis; its prognosis, and treatment options. Women with mobility impairments, in particular, may want information about how the treatment options may affect her disability, function, or mobility. Services that could be provided by social workers may include distributing information, arranging accessible transportation, helping with family concerns, dealing with emotional distress, offering reassurance, and making referrals for medical or community-based services.

Disability Advocacy

Medical and public health social workers must become more involved in disability advocacy and policy work. These social workers often work in multidisciplinary settings and are in unique positions to advocate for agency-wide policies that promote the inclusion of women with disabilities. Medical and public health social workers may be instrumental in making sure that breast cancer screening sites comply with the Americans with Disabilities Act (1990) and the Rehabilitation Act of 1973. The former gives civil rights protection to individuals with disabilities; the latter requires that any program receiving federal financial assistance be accessible to everyone. Knowledgeable social workers can be instrumental in advocating for reasonable modifications in policies, practices, and procedures that will accommodate women with disabilities. For example, social workers may advocate for mammography machines that can accommodate a woman in a seated position, accessible dressing rooms, longer appointment times, or health information in alternative formats.

Conclusion

Social work has not embraced the issues and concerns of the disability community as it has for other underserved populations of women. To meet this challenge, social worker training

and education must be improved. As a profession, social work must examine its attitudes and beliefs about people with disabilities and address disability content in its educational curriculum.

Many medical and public health social workers are in unique positions to affect public policy and influence the delivery of breast cancer screening and treatment services for women with disabilities. Improved training and education, increased collaboration with the disability community, better understanding of disability resources, and persistent disability advocacy can have a substantial effect on the quality of breast cancer screening and treatment services for women with disabilities nationwide.

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APPENDIX A
RECRUITMENT HANDBOOK

Recruitment Handbook

CDC
*Breast Cancer
Screening and
Treatment Study
for Women with
Disabilities*



SAFER • HEALTHIER • PEOPLE

Acknowledgments: The Centers for Disease Control and Prevention, National Center on Birth Defects and Developmental Disabilities (NCBDDD), thanks the Center for Research on Women with Disabilities (CROWD) at Baylor College of Medicine and the Research and Training Center for Independent Living at the University of Kansas for their assistance in developing this Recruitment Handbook.

We have prepared this Recruitment Handbook for you to modify (add your organization's name and logo), reproduce for distribution, and use in your recruitment activities in the community. This manual was funded by the federal government and is not copyright-protected. We encourage you to use this material to help achieve your recruitment goals.

Recruitment Handbook

CDC Breast Cancer Screening and Treatment Study for Women with Disabilities

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Introduction

The “**CDC Breast Cancer Screening and Treatment Study for Women with Disabilities**” is being conducted by the Centers for Disease Control and Prevention (CDC) in collaboration with the Center for Research on Women with Disabilities at Baylor College of Medicine in Houston, the Research and Training Center on Independent Living at the University of Kansas, and the University of Georgia, School of Social Work. Although much research has been done on women with breast cancer, few studies have focused on the breast cancer screening and treatment experiences of women with disabilities. This study will provide information that has not been previously available—information that can help change the way health-care professionals think about women with disabilities and breast cancer; information that can make screening and treatment facilities more accessible; and information that can help women with disabilities better understand their risks for breast cancer and their treatment options.

The purpose of this handbook is to assist you in recruiting women with physical disabilities to participate in the research study on breast cancer and women with disabilities. The materials in this handbook were designed to help ensure your success in recruiting participants—one of the most important parts of any research study. Your participation will assist us in collecting information that could help reduce the risk for cancer in women with disabilities.

This handbook contains four easy-to-follow steps for developing a complete recruitment plan. Also included are sample flyers, press releases, fact sheets, and other resources. These ideas will be new to some of you. For others, the information will simply review strategies you already use to recruit consumers and volunteers for your organization's programs and services.

Feel free to use the material contained in this handbook in ways that work best for you. You are the experts in your community. You know what has worked and what has not worked for you. Consider our ideas and suggestions, but rely on your own knowledge and experience.

The members of the CDC Breast Cancer Research Team thank you for agreeing to assist us with participant recruitment. We appreciate your willingness to work with us on this important project, and we value your commitment of time and effort to make this research a success.

-CDC Breast Cancer Research Team

STEP 1:

Understanding the Process

Before you begin to recruit women, you need to develop a plan for how you will proceed when a woman contacts you about participating in the research study.

Here are some ideas to consider:

1. Make sure the person who answers the phone knows your organization is involved in a research study and knows who will be taking calls about the research project.
2. Ideally, one person (*we strongly recommend a woman*) who is in charge of recruitment should be the contact for the researchers and receive calls from women interested in participating in the study.
3. If the contact person is not always available, make sure the receptionist knows her schedule. The receptionist can then tell women when to call back or when they can expect a return call.

When a woman who is interested in participating in the research study contacts you:

1. Briefly explain the research project (*see telephone script Appendix A*).

2. Ask the woman if she is interested in participating.
3. If she answers YES, ask her the questions on the **Screening Questionnaire** (*see Appendix B*). Record her answers on the form.
4. Review her answers to the questionnaire and determine whether she is eligible to participate in the research study. To be eligible to participate, a woman must:
 - be 40 years old or older;
 - have a physical disability such as those listed on Question #1 of the **Screening Questionnaire**;
 - have had a physical disability for 3 years or more; and
 - be able to give informed consent
5. If the woman is *not* eligible to participate, tell her why she is not eligible. If she would like to learn more about breast cancer, refer her to the American Cancer Society's Cancer Resource Center at 1-800-ACS-2345. Thank her for answering the questions.
6. If she *is* eligible to participate, record her contact information on the **CIL Contact Information Form** (*Appendix C*). Let her know that someone will contact her soon to collect additional information (*Appendix D*).
7. Fax all completed forms to the CDC research team as soon as possible.

STEP 2: Getting the Word Out

For many people, “getting the word out” is the most exciting part of the recruiting process. Publicizing the research study by distributing flyers, contacting newspapers and magazines, and being interviewed on radio or television programs can be a lot of fun.

Publicizing the research study can involve many different tools and techniques for communicating with your target group—in this case women with physical disabilities. A list of techniques and tools will be provided later in this section. For now, let’s focus on the two important parts of an effective publicity strategy: 1) developing the publicity materials and 2) reaching the target group with the message.

The CDC Breast Cancer Research Team has compiled the following publicity materials to assist you in *Appendix I*.

- ✓ News Release
- ✓ Public Service Announcement (PSA)
- ✓ Recruitment Flyer
- ✓ Breast Cancer Facts and Figures
- ✓ Talking Points for Media Interviews

These materials are designed so you can use them as they are or personalize them a little or a lot. For example, you can use the news release as written, adding only your contact name and phone number at the top, or you can change the last paragraphs to include a quote from your Director, and put your city first as "...one of seven U.S study sites." Whether you use the materials as designed or modify them to meet your needs, your goal is to use them and the ideas outlined in this section to get the word out in your local community. Your goal is to inform women with disabilities about the research study and to motivate them to participate.

The CDC and its research partners are committed to the active recruitment of participants representing the diverse communities and cultures of persons with disabilities. As you begin your recruitment activities, consider asking organizations in your area that serve different cultural and ethnic groups if they can help you recruit.

Here are 12 ideas for reaching this goal, along with a list of widely used publicity tools and techniques to further spark your creativity:

- Idea #1:** Send out a letter announcing the research study and the eligibility requirements to the women on your organization's mailing list.
- Idea #2:** Write an article for or place an announcement about the study in your organization's newsletter.

- Idea #3:** Post flyers around your organization, and place them in the reception area.
- Idea #4:** Hold short, informal meetings at your site to provide information about the study to potential participants. Request that peer or support group facilitators pass flyers to participants who might be interested.
- Idea #5:** Ask local chapters of health and disability-related organizations for help in recruiting participants. Consider organizations such as the Lupus Foundation, Scleroderma Foundation, Arthritis Foundation, Multiple Sclerosis Society, Muscular Dystrophy Association, United Cerebral Palsy, Polio Survivors, disability service organizations, and disabled sports teams.
- Idea #6:** Talk to physicians or nurses in medical specialty areas such as rheumatology, cardiology, physical medicine and rehabilitation, and pulmonary medicine. Ask them for referrals. Also ask if you can place flyers in their offices or clinic waiting rooms.
- Idea #7:** Talk to local pharmacists about the study. Place flyers at drug store and supermarket pharmacy counters.
- Idea #8:** Send a news release to health editors or health writers of local newspapers and magazines.

- Idea #9:** Send a public service announcement to local radio stations, especially all-news stations and public radio stations.
- Idea #10:** Contact the assignment editors of local television news programs. Tell them about the research study and ask them to broadcast a story about breast cancer and women with disabilities. Provide them with a breast cancer fact sheet. Offer to help them find women and experts for interviews.
- Idea #11:** Call producers of local television talk shows. Discuss the study and why it is important. Suggest they consider broadcasting a segment or an entire show on breast cancer and women with disabilities. Offer to assist them in finding guests and audience members if the show has a live studio audience.
- Idea #12:** Call producers of local radio talk shows and try the same strategy as #11. Target shows about health or shows that cover health-related topics.

These are only 12 of the many ideas you can use to get the word out to women who may be interested and eligible to participate in the research study. We encourage you to create your own ideas and share them with staff members at the other sites involved in this research project. Here is a list of widely used publicity tools and techniques to use as an additional resource.

Publicity Tools and Techniques

announcements	newsletters
articles	newspaper stories
balloons	newspaper supplements
billboards	news releases
brochures	posters
buttons	personal contacts
direct mail	seminars or workshops
editorials	special events
exhibits	talk shows
fact sheets	t-shirts
feature stories	TV or radio news stories
flyers	video or audio tapes
in-house publications	word of mouth
letters to the editor	

As you put these ideas and techniques into practice, remember that recruitment experts say you must recruit at least twice the number of people needed for your study. Because our goal is to have 8-10 women in each focus group, plus several alternates in case any of the confirmed participants are unable to attend, *you will need to recruit 20 or more women* to end up with enough eligible participants.

STEP 3:

Preparing for the Focus Groups

Focus groups have been used widely in advertising and market research. In recent years, use of this technique has spread into the area of social research.

Focus groups consist of a small group of people who are brought together to explore attitudes, perceptions, feelings, and ideas about a particular topic. The focus group is facilitated by a trained moderator who understands how to encourage group interaction and individual participation, while managing to keep the discussion “focused” on the topic.

The CDC Breast Cancer Research Team members will conduct and moderate the focus groups. The focus group discussions will be captured word for word using a court stenographer or court reporter. As a local research site, your role is to help organize and coordinate. If you are following the steps outlined in this handbook, you have already designated a female staff person to serve as the local contact person for the focus group participants. This person should also be responsible for overseeing the following arrangements in a timely and professional manner:

1. Maintain communications with the CDC research team in planning the focus groups.

2. Obtain contact and fee information about local court reporting services, and provide this information to the CDC research team.
3. Recruit enough women who meet the eligibility requirements so each focus group will have at least 8 participants.
4. Send all survey and information forms to the CDC research team in a timely manner.
5. Find meeting space that will protect participants' privacy and that meets accessibility requirements specified by the Americans with Disabilities Act. Make sure the space will hold 15 people seated around a table.
6. Arrange for any accommodations needed by individual focus group participants, such as sign language interpreters or alternative formats.
7. Arrange for accessible transportation for focus group participants, as needed.
8. Mail out an official letter of invitation that outlines the date, time, and location of the focus group (*Appendix E*).
9. Make reminder calls to participants 48 hours before the focus group meeting (*Appendix F*). Arrange for alternates to replace any focus group member who is unable to confirm her participation at this time (*Appendix G*).

10. Provide refreshments for participants during the focus group sessions.
11. Be present on the day of the focus group sessions to provide on-site support as needed.
12. Distribute thank-you letters and follow-up packets to participants when the study is completed (*Appendix H*).

Before the research project begins, your organization will be asked to sign a contract letter agreeing to carry out the responsibilities as stated above. The contract will also include a list of the specific responsibilities of the CDC Breast Cancer Research Team in the planning and preparation of the focus group sessions. These responsibilities also are outlined below.

The CDC Breast Cancer Research Team will be responsible for:

1. Reimbursing your organization as specified in the financial agreement.
2. Negotiating a mutually acceptable date to hold the focus group(s).
3. Maintaining communications with the staff person you have assigned to this project.
4. Providing materials for the recruitment of focus group participants.

5. Scheduling and paying for court reporting services for the focus groups.
6. Processing payment for participation and transportation reimbursements for focus group participants.
7. Facilitating the focus group sessions.

As you begin to prepare for your focus group sessions, please feel free to call the CDC researchers with any questions or challenges. For easy reference, the CDC researchers, project sites, and local contacts are included in *Appendix J*.

STEP 4: Following Up

Many research projects offer participants a small payment in exchange for their participation; for example, our participants will receive \$30 per focus group session. The small amount of money offered is usually not enough to equal the amount of time and effort most participants give.

Additional benefits of participating in a research study include meeting new and interesting people and helping others. Still, there is no substitute for trying to make participants feel valued and appreciated. This is why following up is so important!

Follow-up activities that include providing payment for participation and reimbursement for travel in a timely manner, sending a well-written thank-you letter, and sharing results after the research study is completed can help to ensure each participant feels that working with us was a positive and valuable experience.

The CDC Breast Cancer Research Team will handle payment and reimbursement and will develop a follow-up packet that includes a thank-you letter and a summary of the important findings from the research study. We ask that you be responsible for two follow-up activities:

1. Distribute the thank-you letters and follow-up materials

to everyone who participated in the focus groups; and

2. Handle or refer to the CDC researchers any follow-up questions women have about the research study.

With this handbook, we have tried to outline all the important steps and cover the essential aspects of the entire recruiting process. We fully expect that questions or issues we have not anticipated will arise. The key to our success in dealing with these will be good communications. Always feel free to call the CDC research team with any questions or challenges.

Appendices

A. Telephone Script

Explanation of Research Project

Telephone Script

The Centers for Disease Control and Prevention (CDC), Baylor College of Medicine, the University of Kansas, and the University of Georgia are doing research about breast cancer screening and treatment for women with physical disabilities. They are doing this research to learn about the problems disabled women have getting cancer screening and treatment. The research involves a focus group discussion that will last about 2 hours. The researchers will ask you questions about cancer risks, health-care providers, personal behaviors, and barriers to screening and treatment. Is this something in which you might be interested in participating?

B. Screening Questionnaire

Screening Questionnaire

CDC Breast Cancer Screening and Treatment Study for Women with Disabilities

To be completed by CIL Staff

1. Are you limited in any way in any activities because of physical problems?

- Yes Don't know/Not sure
 No Refused

2. Do you now have any health problem that requires you to use any of the following special equipment? (Read list and check off appropriate boxes)

- | | |
|--|--|
| <input type="checkbox"/> Crutches | <input type="checkbox"/> Manual Wheelchair |
| <input type="checkbox"/> Cane | <input type="checkbox"/> Power Wheelchair |
| <input type="checkbox"/> 3-Wheeled Cart | <input type="checkbox"/> Ventilator |
| <input type="checkbox"/> Braces or Other Orthotic Device | <input type="checkbox"/> Hospital Bed |
| <input type="checkbox"/> Artificial Limb or Other Prosthetic | <input type="checkbox"/> Other: _____ |
| <input type="checkbox"/> Walker | |

3. How would you identify your primary disability?

- | | |
|--|---|
| <input type="checkbox"/> Spinal Cord Injury | <input type="checkbox"/> Polio/Post-Polio |
| <input type="checkbox"/> Cerebral Palsy | <input type="checkbox"/> Stroke |
| <input type="checkbox"/> Muscular Dystrophy | <input type="checkbox"/> Spina Bifida |
| <input type="checkbox"/> Joint and Connective Tissue Disease
(such as Lupus, Scleroderma, or Arthritis) | |
| <input type="checkbox"/> Traumatic Brain Injury with Loss of Physical Function | |
| <input type="checkbox"/> Amputation: Type _____ | |
| <input type="checkbox"/> Other _____ | |

4. How old were you when the condition first occurred? _____

5. How old were you when the condition was first diagnosed? _____

6. What year were you born? _____

(Must be born before 1961 to participate)

7. With which cultural heritage or ethnic group do you identify?

- Native American
- Asian or Pacific Islander
- Black, Non-Hispanic
- Black, Hispanic
- White, Non-Hispanic
- White, Hispanic
- Other and Unknown: _____

8. How did you hear about this research study?

- This woman is interested and **may be eligible** to participate in this research study. Please contact her.
- This woman is interested but **not eligible** to participate in this research study. Explain why she is not eligible. If she would like to learn more about breast cancer, refer her to the American Cancer Society's Cancer Resource Center at 1-800-ACS-2345. Stop.
- This woman is **not interested** in this research study. Stop.

If you think the woman is eligible, continue with the CONTACT INFORMATION Form.

CIL _____

Form completed by _____ date _____

Form Faxed to CDC Coordination Office _____ date _____

C. CIL Contact Information Form

ID# _____

CIL Contact Information Form

CDC Breast Cancer Screening and Treatment Study for Women with Disabilities

To be completed by CIL Staff

- This woman is interested and *may be eligible* to participate in this research study. Please contact her.

Name _____

Address _____

City _____ **State** _____ **Zip** _____

Phone number (day) _____ **Phone number (evening)** _____

E-mail address _____

CIL _____

Form completed by _____ **date** _____

Form Faxed to CDC Coordination Office _____ **date** _____

The CDC Research Team will make final decisions about eligibility.

D. Researcher Contact Information Form

Researcher Contact Information Form

CDC Breast Cancer Screening and Treatment Study for Women with Disabilities

To be completed by staff from the University of Kansas or Baylor College of Medicine

1. A clinical breast exam is when a doctor, nurse, or other health professional feels the breast for lumps. Have you ever had a clinical breast exam?

- Yes Don't know
 No Refused

2. A mammogram is an x-ray of each breast to look for cancer. Have you ever had a mammogram? (If no, skip to question 4)

- Yes Don't know
 No Refused

3. How long has it been since you had your last mammogram ?

- Within the past year (anytime less than 12 months ago)
 Within the past 2 years (1 year but less than 2 years ago)
 Within the past 3 years (2 years but less than 3 years ago)
 Within the past 5 years (3 years but less than 5 years ago)
 Don't know
 Refused

4. Have you ever been diagnosed or treated for breast cancer?

- Yes Don't know
 No Refused

5. Will you be able to attend a focus group on (date, time, location)?

- Yes No

If yes, will you need transportation or other special accommodations?

- This woman is **not eligible** to participate in this research study. Explain why she is not eligible. If she would like to learn more about breast cancer, refer her to the American Cancer Society's Cancer Resource Center at 1-800-ACS-2345.

- This woman is **eligible** to participate in this research study. She should be assigned to:
 - Group A Group B Group C

 - Alternate List/Group_____

Form completed by _____ date _____

E. Letter of Invitation

[Official Letterhead]

[Name and address of participant]

[Date]

Dear _____:

Thank you for agreeing to take part in the Centers for Disease Control and Prevention (CDC) study on breast cancer screening and treatment for women with physical disabilities. The focus group will meet on [day, date, and time] at [location].

You will be joining a focus group with other women with disabilities. You will talk about your concerns and experiences with breast cancer screening and treatment. The discussion will last two hours. After your focus group, we will give you \$30.00. This is to help repay you for the time you spend with us and the cost of coming to our study.

If you told us you need help with transportation or have other special needs, someone will call you soon to make those arrangements. You will get a phone call two days before the meeting to reconfirm your participation. At that time, we will review your transportation plans and other special needs.

We are talking to a small number of women. The success of our discussion depends on your participation. If for some reason you can't come, please let us know as soon as possible so we can ask another woman to take your place. Our phone number is [].

Thank you for agreeing to take part in this study. The information that you share will be helpful to us in learning about the breast cancer screening and treatment needs of women with disabilities.

Sincerely,

[CIL contact]

F. Protocol for Focus Group Reminder Calls

Protocol for Focus Group Reminder Calls

Reminder calls should be made 48 hours before the meeting. Please keep calling until you are able to reach each participant, because this personal contact may be an important factor in her final decision to attend.

1. Call the participant, and if she is not home, either leave a message on her answering machine or ask the person who answers when and where you might reach her. (Be sure to ask if it is ok to call her at another location.)
2. When you reach her, use the following script:

"This is ___[name]___ calling you from ___[CIL]___ to remind you about the focus group on breast cancer [screening or treatment] that will be held on ___[date] ___ from ___[time] ___ at ___[location]___. Are you still planning to attend?"

If **no**, thank her and end the call.

If **yes**, review transportation arrangements and other requests for reasonable accommodations.

3. Terminate the call using the following script:

"Thank you for your willingness to participate in this focus group. Please call our office at _____ if you need any further assistance. We look forward to seeing you at the meeting. Good-bye."

G. Protocol for Focus Group Alternate Calls

Protocol for Focus Group Alternate Calls

Calls may be made up to 4 hours before the focus group begins. The research team will not be able to provide special transportation for these participants as these arrangements are likely to take more than 48 hours to schedule.

1. Check the list of alternate attendees and call one of them. If she is not home, do not leave a message; move to the next name on the list.
2. When you reach her, use the following script:

"This is ____ [name] _____ calling you from ____ [CIL] _____ regarding our study on breast cancer screening and treatment for women with physical disabilities. You had indicated that you might be willing to participate in one of our focus groups if another woman canceled. Are you still interested in participating?"

If **no**, thank her and end the call.

If **yes**, continue with the following script:

"The meeting will be held on ____ [date] _____, from ____ [time] _____ at ____ [location] _____. Are you able to participate at this time?"

If **no**, thank her, and end the call.

If **yes**, confirm the invitation, and review the date, time, and location of the meeting.

3. Terminate the call using the following script:

"Thank you for your willingness to participate in this focus group. Please call our office at _____ if you need any further assistance. We look forward to seeing you at the meeting. Good-bye."

H. Thank-you Letter

[Official Letterhead]

[Name and address of participant]

[Date]

Dear _____:

Thank you for taking part in the Centers for Disease Control and Prevention (CDC) study on breast cancer screening and treatment for women with physical disabilities. Your participation in our focus group will tell us a lot about barriers to breast cancer screening and treatment among disabled women.

When we finish the study, we will send a complete report of our findings to each study site. They will then forward the information to you. We will also post our findings on the CDC website at <http://www.cdc.gov/ncbddd/dh>.

Thank you for taking part in our study. We appreciate your commitment of time and effort in making this research a success.

- CDC Breast Cancer Research Team

I. Publicity Materials

News Release

for further information contact:
JoAnn Thierry, (770) 488-7097

Women with disabilities at risk for breast cancer face barriers to treatment

Your City — [insert release date here] — Women with disabilities are at risk for breast cancer, yet physical and attitudinal barriers continue to contribute to their not getting screened. Researchers at the Centers for Disease Control and Prevention (CDC) in Atlanta, the Center for Research on Women with Disabilities (CROWD) at Baylor College of Medicine in Houston, the Research and Training Center on Independent Living at the University of Kansas, and the University of Georgia School of Social Work have joined forces to study this problem.

The study will examine the degree of difficulty and the types of barriers that women with disabilities face when seeking preventive care and breast cancer treatment. “Research so far has shown that older women with more limitations are less likely to receive mammograms. We want to know why,” said JoAnn Thierry, behavioral scientist for CDC and principal investigator for the study.

“Women with disabilities need to know that they, too, need to do regular breast self-exams,” said Dr. Margaret A. Nosek, co-investigator and director of CROWD. “If their

disability prevents them from doing so, they need to have someone else close to them do it.” Nosek added, “Mammography equipment is often inaccessible. If a woman is in a wheelchair and can’t stand, it would be difficult for her to get a mammogram.”

According to Dr. Glen White, co-investigator and director of the Research and Training on Independent Living, the study will also examine physician attitudes toward women with disabilities. “We want to find out if women with disabilities who are diagnosed with breast cancer are given the same treatment options as women without disabilities,” said White.

“We are pleased that Baylor College of Medicine, the University of Kansas, and the University of Georgia are collaborating with us on this important study,” said the CDC’s JoAnn Thierry. “We believe that having a better understanding of these critical barriers will lead to improved interventions directed at reducing cancer mortality among women with disabilities.” Research will be conducted in seven U.S. cities: Oakland, California; Denver, Colorado; Washington, D.C.; Boston, Massachusetts; Rochester, Minnesota; Jackson, Mississippi; and Houston, Texas.

###

Public Service Announcement

Women needed for new breast cancer research study

Your City—[insert release date here]—Women with physical disabilities are needed for a new research study on breast cancer conducted by the Centers for Disease Control and Prevention. Women will be asked to participate in focus groups to help identify barriers faced by women with disabilities when they seek preventive care and treatment for breast cancer. Qualified participants will be compensated for their time. To find out how you can sign up to participate in this study, call [insert name and phone number of your organization here].

Recruitment Flyer

Would You Like to Help Reduce the Barriers to Breast Cancer Screening and Treatment For Women with Disabilities?

Special focus groups will be conducted at the
[insert your location here]

As a focus group participant, you will be part of a research study that will identify barriers faced by women with disabilities when they seek preventive care and treatment for breast cancer.

If you qualify, you will receive a small payment for your participation. To find out more, call the
[insert your organization here]

Space is limited, so call today.
[insert phone number here]

The research is being conducted by the Centers for Disease Control and Prevention in collaboration with the Center for Research on Women with Disabilities at Baylor College of Medicine, the Research and Training Center on Independent Living at the University of Kansas and the University of Georgia.

Breast Cancer Facts & Figures

- This year, an estimated 182,800 new cases of invasive breast cancer will be diagnosed in American women, and an estimated 40,800 women will die from this disease.
- Women with disabilities are just as likely to be at risk for breast cancer as women in the general population; the biggest risk factors are being a woman and aging.
- The lifetime risk for breast cancer is 1 in 8, the chances of getting breast cancer by age 50 are 1 in 54. By age 60, the chances are 1 in 23.
- Breast cancer cannot be prevented.
- Early diagnosis is the key to surviving breast cancer. Nearly 97% of women in whom breast cancer is diagnosed at an early stage survive for more than 5 years.
- Mammography can detect cancers several years before a woman or her health-care provider can feel a lump.
- Adjustable-height examination tables and accessible mammography equipment are available that can accommodate many women with physical limitations.
- Low-cost and free mammograms are available to low-income women through their local or state health department.

References

American Cancer Society. Cancer facts and figures—1999. Atlanta, GA: American Cancer Society, 1999.

Website: www.cancer.org

Centers for Disease Control and Prevention. Use of cervical and breast cancer screening among women with and without functional limitations—United States, 1994-1995. MMWR 1998;47:853-856.

Centers for Disease Control and Prevention. Implementing recommendations for the early detection of breast and cervical cancer among low-income women. In: CDC recommendations regarding selected conditions affecting women's health. MMWR 2000;49 (RR-2):37-55.

Talking Points For Media Interviews*

The interview process usually begins with a call from a reporter. Ask the reporter what the story is about and what type of story it is (e.g., hard news, feature, investigative report). Ask how you fit in the story and request information about the interview format (e.g., by telephone, in person, on camera). Agree upon a time for the interview, and **HANG UP THE PHONE**. Don't answer any questions unless you are fully prepared. Stop and think about your answers. Are you the best person to respond? Decide what you can say and how you can say it.

You should never go into an interview just to answer a reporter's questions. Have your own agenda (e.g., a point you want to make about the positive things you are doing). Develop the messages you want to get out. These messages should be **simple, single, and succinct**. During the interview, restate the objective message in every answer. If you answer a dozen questions and remember to include your objective only six times, there's a good chance your message will wind up on the cutting room floor. Reporters are used to hearing repeated messages from experienced interview subjects.

Whenever possible, turn your message into a sound bite. A sound bite is a quotable quote, not a long explanation of a complex issue. A typical sound bite is 10-15 seconds—2 or 3 short sentences. Turn your objective into a sound bite using this formula: (For this example, our objective will be to inform the public about our study and recruit participants).

Element	Example
<p>Conclusion A sound bite always begins with the conclusion.</p>	<p>“CDC is recruiting women with physical disabilities for a new research study exploring breast cancer screening and treatment.”</p>
<p>Evidence Offer one or two brief points of explanation, elaboration, or support.</p>	<p>“Women with disabilities are at risk for breast cancer, yet physical and attitudinal barriers continue to contribute to their not getting screened. These barriers may include lack of transportation, inaccessibility of facilities and equipment, and difficulty mounting standard exam tables.”</p> <p style="text-align: center;">-or-</p> <p>“Most health-care professionals have not been adequately trained to address problems and issues related to disability, and as a result, women with disabilities are not getting screened for diseases such as breast cancer.”</p>
<p>Meaning Explain how your message will affect the viewers/readers or what action you want them to take.</p>	<p>“We need to make sure our clinics and testing sites are accessible to all women, including women with disabilities, and this study will help us do that. To find out how you can participate in this research, call [name and phone number of local organization].”</p> <p style="text-align: center;">-or-</p> <p>“Providers of screening services must be educated about the special health-care needs of women with disabilities, and this research will help us do that. To find out how you can participate in this research, call [name and phone number of local organization].”</p> <p style="text-align: center;">-or-</p> <p>“Once we understand the issues disabled women face regarding breast cancer screening and treatment, we can develop educational programs that help them get the health care they need. This study will help us do that. To find out how you can participate in this research, call [name and phone number of local organization].”</p>

Achieving your objective may be difficult when the reporter asks an unrelated question. Use the “bridging” technique. Touch on the answer to the reporter’s question, and go on -bridge- to your own objective. Don’t wait for the reporter to ask the perfect question. It may never happen. Following are some useful transition phrases that will help you deliver your message.

- ◆ That’s an interesting question. It reminds me of...
- ◆ Before I forget, I want to tell your audience...
- ◆ Let me put it in perspective...
- ◆ What’s important to remember, however...
- ◆ What I really want to talk to you about is...
- ◆ What’s most important is...
- ◆ And don’t forget...
- ◆ Before we get off the subject/topic let me add...
- ◆ That’s a good point, but I think your audience would be interested in knowing that...
- ◆ What I’m really here to talk to you about is...
- ◆ Let me just add...
- ◆ That reminds me...
- ◆ Let me answer you by saying that...
- ◆ Let me give you some background information...
- ◆ Let’s take a closer look at...
- ◆ That’s an important point because...
- ◆ What that means is...
- ◆ Another thing to remember is...
- ◆ Now that you’ve covered_____, let’s move on to_____...
- ◆ You may be asking why_____is true...
- ◆ Although_____is certainly important, don’t forget that_____...
- ◆ As I said..._____.

* Adapted from Hartman NM; The media & you: a basic survival guide. National Public Health Information Coalition, 1993. Printed and distributed by the Centers for Disease Control and Prevention.

J. CDC Research Team Project Sites and Local Contacts

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APPENDIX B
GUIDELINES FOR ASSISTANT MODERATORS

GUIDELINES FOR ASSISTANT MODERATORS

1. **Take responsibility for all equipment.** Make sure the equipment (e.g. tape recorder, microphone, blank tapes, extra batteries, extension cords, name tags) is present and works properly.
2. **Arrange the room.** Rearrange the tables and chairs to accommodate participants. Make sure the participants can see each other.
3. **Set up the equipment.** Test the equipment and verify that it is working properly.
4. **Help welcome participants as they arrive.**
5. **Sit in the designated location.** Sit opposite the moderator and close to the door. If someone arrives after the session begins, meet the person at the door, take her outside the room and get informed consent. Give her a brief description as to what has happened and the current topic of discussion. Bring the late participant into the room and show her where to sit.
6. **Take notes throughout the discussion.** Pay close attention to the following:
 - *Notable quotes.* Capture word for word as much of the statement as possible. Listen for phrases that are particularly eloquent. Place quotation marks around the statement and indicate the first name of the speaker. Place your opinions; thoughts or ideas in parentheses to keep them separate from participant comments. If a question occurs to you that you would like to ask at the end of the discussion, write it down and circle it.
 - *Note the nonverbal activity.* Watch for head nods, eye contact, or other cues that would indicate level of agreement, support, or interest.
 - *Make a sketch of the seating arrangement.*
7. **Monitor recording equipment.** Occasionally glance at the tape recorder to see if it is working. Turn over the tape or insert another tape when appropriate. Label the cassette tapes. Indicate the date, location, and number of each tape.
8. **Ask questions when invited.** At the end of the discussion, the moderator will invite you to ask questions of elaboration or clarification.
9. **Give an oral summary.** At the end of the discussion, the moderator will ask you to provide a brief summary (about 2-3 minutes) of responses to the important questions. The moderator will invite participants to offer additions or corrections to the summary.

10. Pay participants.

11. Debrief the session with the moderator. Immediately following the focus group, participate in the debriefing with the moderator. Record first impressions and then highlight and contrast important findings from previous focus groups.

12. Read and provide feedback on the analysis.

Source: Adapted from Krueger, RA (1994). Focus groups: A practical guide for applied research. Sage Publications: London

APPENDIX C
DISCUSSION GUIDE OUTLINES

Discussion Guide Outlines

Group A/Never Been Screened or Not Screened Within Recommended Guidelines.

- I. Background and Introductions (10 minutes)
- II. General Attitudes, Practices, and Experiences Regarding Health Care (30 minutes)
- III. General Understanding of Risk and Purpose of Recommended Frequency for Clinical Breast Exams and Mammograms (30 minutes)
 - A. Purpose of Clinical Breast Exams and Mammograms
 - B. Frequency
 - C. Perception of Risk
 - D. Breast Cancer
- IV. Reasons for Not Getting Screened (30 minutes)
- V. Summary of Ideas and Suggestions (10 minutes)
- VI. Closing and Departure (10 minutes)

Total Time: 120 minutes

Group B/Screen Within Recommended Guidelines.

- I. Background and Introductions (10 minutes)
- II. General Understanding of Risk and Purpose of Recommended Frequency for Clinical Breast Exams and Mammograms (30 minutes)
 - A. Purpose of Clinical Breast Exams and Mammograms
 - B. Frequency
 - C. Perception of Risk
 - D. Breast Cancer
- III. Experiences with Breast Exams and Mammograms (30 minutes)
 - A. Reasons for Getting Most Recent Breast Exam or Mammogram
 - B. Timing, Logistics, and Accessibility

- C. Breast Exam Experience
 - D. Mammogram Experience
 - E. Concerns and Questions About Breast Exams and Mammograms
- IV. Response to Results of Mammogram (30 minutes)
 - V. Summary of Ideas and Suggestions (10 minutes)
 - VI. Closing and Departure (10 minutes)

Total Time: 120 minutes

Group C/Treatment

- I. Background and Introductions (10 minutes)
- II. Experiences with Breast Exams and Mammograms (30 minutes)
 - A. Reasons for Getting Most Recent Breast Exam or Mammogram
 - B. Timing, Logistics, and Accessibility
 - C. Breast Exam Experience
 - D. Mammogram Experience
 - E. Concerns and Questions About Breast Exams and Mammograms
- III. Response to Results of Mammogram (30 minutes)
- IV. Experience with Diagnosis and Treatment (30 minutes)
 - a. Diagnosis
 - b. Treatment
 - c. Recovery
 - d. Social Support
- V. Summary of Ideas and Suggestions (10 minutes)
- VI. Closing and Departure (10 minutes)

Total Time: 120 minutes

APPENDIX D
MODERATOR DISCUSSION GUIDE

Moderator Discussion Guide

Please note: This document is a GUIDE only; not a script from which you will read questions verbatim. You should adapt the wording of the questions and the order in which you introduce them according to best suit each group of women, the specific dynamics of each group, and comments from the participants. All text in this document that is not printed in bold is information only for you, the moderator(s), so this information probably contains some words or references that you will not use in your discussions with the participants.

Target Audiences:

Women with physical disabilities.....

- Including but not limited to: spinal cord injury, cerebral palsy, muscular dystrophy, polio/post-polio, stroke, spina bifida, joint and connective tissue disease (e.g., lupus, scleroderma, or arthritis), traumatic brain injury with loss of physical function, and amputation.
- Who are 40 years of age or older
- Who have had a disability for a minimum of 3 years
- and-
- Who have never received a mammogram or have not received one within the recommended guidelines (Group A)
- or-
- Who have received a mammogram within the recommended guidelines (Group B)
- or-
- Who have survived breast cancer (Group C)

I Background and Introductions (10 minutes) Groups A, B, & C

Objective: To explain the purpose of and procedures for the group and to facilitate introductions to help participants become comfortable with each other and with you.

You Should:

- Thank participants for attending.
- Introduce yourself.
- Explain that the purpose of the discussion is to hear about experiences with and feelings about breast cancer screening and treatment. Point out what everyone has in common (i.e., they have never received a mammogram; have been screened (had a mammogram) at least once, or have survived breast cancer).
- Review informed consent.
- Emphasize that no answers are right or wrong and that everyone should feel free to talk honestly about their opinions.

- Emphasize that participants do not have to answer questions they are uncomfortable about answering.
- Emphasize that names will not be used in any report about the discussion.
- Explain the presence and purpose of the recorders, recording devices, and any observers.
- Facilitate participants' self-introductions.

(Note: To help the women feel more at ease about speaking in a group, ask them to share something about themselves during the introductions. This gives participants an opportunity to address an "easy" topic before the formal discussion of more difficult topics begin. You can pose a warm-up question that is easy for participants to answer and cannot be construed as having a "right" or "wrong" answer (e.g., "tell us something about yourself" or "tell us what you enjoy doing in your spare time.")

(Note: Throughout the discussion, you will need to adjust the wording of questions to fit with what participants have or have not already brought up.)

II General Attitudes, Practices, and Experiences Regarding Health Care (30 minutes) Group A

Objective: To explore how often women with disabilities see a doctor and for what reasons. This will enable the research team to learn about differences between attitudes and behaviors.

The main thing we will be talking about will be your thoughts and feelings about breast cancer screening. But first, I'd like to hear a little bit about other reasons you might go to see a doctor or nurse. Sometimes women tell us they go to a doctor or nurse fairly often; others tell us they do not go very often.

What is usual for you?

For women who don't go to the doctor.....**Is there a particular reason you don't go to the doctor?**

How often do you go to a doctor or nurse for yourself (rather than for your children, spouse, parents, or other person)?

What kinds of things have you gone to a doctor for in the last year or so?

You should probe to determine whether women go for symptoms only, preventive care, speciality care, or some combination of these.

Where do you usually go for your health care (e.g., doctor's office/clinic, speciality clinic, emergency room)?

There are different kinds of tests that you can get during a visit. Are there any tests you have had in the past year? Such as...

Explore participants' responses to determine more about the attitudes and beliefs about tests they have mentioned. For example, the following topics might be explored:

**Why did you get the test?
Did you understand the purpose of the test?
How frequently do you get the test?
Is there any discomfort or pain during the test?**

Explore both positive and negative experiences associated with these tests.

Have you ever delayed getting health care? What were the main reasons you didn't get care?

Explore participants' reasons for not getting care. For example, you can ask:

**Was it because of cost?
Was it because of insurance?
Was it because of other barriers? Such as....**

(Note: Encourage as much discussion as possible about actual and perceived barriers to care.)

III General Understanding of Risk and Purpose of Recommended Frequency for Clinical Breast Exams and Mammograms (30 minutes)

Groups A & B

Objective: To learn what disabled women understand about clinical breast exams and mammograms and the extent to which they believe and trust them as valuable screening tools for early detection of breast cancer.

A. Purpose of Clinical Breast Exams and Mammograms:

Everyone here has (choose one never been screened for breast cancer, or been screened at least once for breast cancer). Let's talk about what these screening tests are for.

For example, what is the doctor or nurse looking for when she or he examines your breasts?

Now let's talk about mammograms. First of all, what is a mammogram? (If no one answers, tell the participants that it is an X-ray of the breast. Emphasize that the procedure is safe and the machines are preset to use the smallest amount of radiation.) **In your own words, how would you describe what it is for?**

Now I am going to read a statement that I would like to get your reactions to:

“Studies have shown that mammograms are the best way to find breast cancer early when it is easiest to treat.”

When you hear that statement, what thoughts come to mind? For example, do you believe this is true? Why or why not? What else have you heard?

B. Frequency

What have you heard about HOW OFTEN women are supposed to go for breast exams and mammograms?

How often do you think YOU should go?

Is the recommendation about how often we are supposed to go different for different groups of women?

C. Perception of Risk

What are some of the risk factors that you have heard about that might increase a woman's chance of developing breast cancer?

Is breast cancer something you personally worry about? Why or why not?

D. Breast Cancer

What proportion of women do you think will get breast cancer at some time during their lives?

If no one responds....., **Would you say 1 in 5? 1 in 10? 1 in 25? 1 in 50?**

Has anyone ever known someone with breast cancer?

For example, has someone in your family or a friend ever had breast cancer?

If yes, briefly explore participants' experiences.

(Note: Giving participants the opportunity to speak about personal experiences with cancer is important. However, no one will be pressed to talk about it if they do not wish to.)

IV Reasons for Not Getting Screened (30 minutes)
Group A

Objective: To understand why women with disabilities do not receive recommended screenings.

Why do you think some women do not get screened for breast cancer?

Are there particular reasons why you have not had a mammogram? Such as...

Probe factors that influenced why the women did not to go for a mammogram. For example, the following may be explored:

Was it because your doctor or nurse never recommended it?

Was it because someone recommended against it?

Was it because of fear?

If yes, encourage as much discussion about fear as possible.

What frightens you?

Fear of pain or discomfort?

Fear of radiation?

Fear of finding cancer?

Was it because you were embarrassed?

Was it because of cost?

Was it because of accessibility?

If yes, encourage as much discussion about accessibility as possible. For example:

Was it lack of accessible transportation?

Was it lack of accessible equipment?

Was it lack of personal assistance?

Was it lack of time?

Was it because you never thought about it?

Was it a combination of the above?

Are there other reasons?

V Experiences with Breast Exams and Mammograms (30 minutes)
Groups B & C

Objective: To obtain information about the factors that promote or discourage disabled women from obtaining breast exams or mammograms.

A. Reasons for Getting Most Recent Breast Exam or Mammogram

For Group B.....Now we would like you to think back to your most recent breast exam and mammogram. For Group C Now we would like you to think back to the breast exam and mammogram before you learned you had breast cancer.

What was the main reason you decided to go?

Probe factors that influenced the decision to go for a mammogram.
For example:

Was it because a doctor or nurse recommended it?
Was it because a friend or family said to?
Was it because of a lump or other symptoms?
Was it because of a combination of the above?
Was it for other reasons?

B. Timing, Logistics, and Accessibility

When

Do you remember HOW LONG AGO it was?

Where

Where did you call to make an appointment. Why there?

Response to Staff

Were the people you talked to friendly?

Were the people you talked to helpful:?

Do you wish they had been different in any way?

Were the staff sensitive to your disability-related issues?

Do you wish they had been different in any way?

Did you have any questions for them when you called?

How did they handle your questions?

Accessibility

Was the facility accessible to you? Why or why not?

Was the equipment accessible to you? Why or why not?

Do you wish it had been different in any way?

Convenience

Was it easy or difficult to get an appointment that was convenient for you to go for the breast exam and mammogram?

How long was it from the time you called until you could get an appointment?

Tell us about how you were able to keep your appointment.

For example, were you able to.....

secure accessible transportation?

arrange child care?

take time off from work?

Companionship/Personal Assistance

Did anyone go with you? Do you wish someone had?

Cost

How much did it COST you if there was a charge?

What about other things you had to pay for like.....

transportation?

babysitting?

taking time off work?

Was there anything else you had to pay for yourself?

C. Breast Exam Experience

(Note: Mammograms are discussed separately below)

Let's talk about the breast exam first. Then we'll talk about the mammogram. If a friend with a disability had never had a breast exam and asked you to tell her about it, how would you describe what happens and what it is like?

If not mentioned...Was there any discomfort or pain of any kind while the doctor or nurse examined your breasts? If yes...

How would you describe that part of the exam? (Encourage as much discussion as possible about pain.)

Did you have any other concerns or questions that you wanted to ask about the exam? Such as...

Is there anything you wish they would do differently? Such as...

D. Mammogram Experience

Now let's talk about the mammogram. Suppose your friend had never had a mammogram: let's talk about what kinds of things you

would tell her about what that's like.

If not mentioned...**Was there any discomfort or pain of any kind during the mammogram?** If yes... **How would you describe it?**

Were you told ahead of time that the mammogram could be uncomfortable? Were you given any advice about how to reduce the pain or discomfort the next time?

Did you experience difficulties with positioning because of your disabling condition? How were these resolved?

Is there anything you wish they would do differently? Such as....

E. Concerns and Questions About Breast Exams and Mammograms

Did you have any other concerns or questions that you wanted to ask about the breast exam or mammogram?

Did you feel that you could talk about your concerns or questions during your visit? Why or why not?

VI Response to Results of Mammogram (30 minutes)

Groups B & C

Objective: To characterize the awareness of and response to mammogram results and recommendations to return for a follow-up mammogram.

Obtaining Results

Did you get the results of your mammogram?

(Note: Some women may not know their results and/or that the results included a recommendation for re-screening within a particular timeframe.) If all women in the group DID obtain results, proceed with questions for women who DID obtain results.)

For Women Who Said They Did Not Obtain Results

Do you have any ideas about why you did not get the results?

Were you surprised that you did not get the results?

Did you think about calling to find out the results? Why or why not?

(Note: Probe gently to learn what women who did not obtain results reveal about their efforts, if any, to obtain results.)

Potential probes.....

Sometimes women say that the real reason they do not call for results is that they are AFRAID to find out. Did you feel that way?

Were there any OTHER REASONS that you did not call?

How likely are you to return for another mammogram?

For Women Who Say They Did Receive Results

How did you hear about the results of your mammogram? How soon afterward?

If the results were given over the phone.....

**Who gave you the results of your test?
Was the person you talked to friendly? Helpful?**

**Did you have any questions for the person when he or she called?
How did the person handle your questions or concerns?**

Do you wish he or she had been different in any way?

Were the results sent to you in writing?

How would you describe what the results were?

Was there anything confusing or hard to understand about the results?

**Did you ask any questions about the results?
If yes further explore.**

Were there any recommendations along with the results?

What was the recommendation?

How likely are you to return for another mammogram?

**VII Experience with Diagnosis and Treatment (30 minutes)
Group C**

Objective: To understand diagnosis and treatment experiences of women with disabilities.

(Note: Everyone in this group is a survivor of breast cancer. Therefore giving participants the opportunity to speak about their personal experiences with cancer is important. However, no one will be pressed to talk about it if they do not wish to.)

A. Diagnosis

How did you learn you had breast cancer?

How did you feel when you found out you had breast cancer?

B. Treatment

There are several treatment methods (e.g., surgery, radiation therapy, chemotherapy, high-dose chemotherapy, hormone therapy, immunotherapy) **available for breast cancer.**

What were your treatment choices?

How did you feel about these options?

Were you able to obtain information about these choices?

If yes....Where did you get this information?

Did someone explain the risks and possible side effects of each treatment? Who?

Did you get a second opinion about your diagnosis and treatment plan?

How did you prepare for treatment?

How did you feel during treatment?

Did you experience any pain or discomfort during treatment?

C. Recovery

Rehabilitation is a very important part of breast cancer recovery.

How did the treatment affect your disability or functioning?

Were you referred for physical therapy?

How long did it take to get back to your normal activities?

D. Social Support

Women with breast cancer usually have many different and confusing emotions. These are normal reactions when people face a serious health problem.

Is there someone who will listen to you when you need to talk?

Who?

Probe to determine who women with disabilities go to for support (e.g., doctor, nurse, social worker, counselor,

volunteer, member of the clergy, family, friends.)

Did you receive any help from rehabilitation professionals?

Such as....

Did you receive any help from community support groups?

Such as...

VIII Summary of Ideas and Suggestions (10 minutes)

Groups A, B, & C

Objective: Obtain ideas and suggestions from women about what would help disabled women get recommended breast exams and mammograms.

Adjust wording for the different focus groups.

We have talked about different things that have helped you or discouraged you from getting the breast exams and mammograms that are recommended. We're just about out of time now, so we have just a few more things to talk about:

For Women Who Have Never Been Screened (Group A)

What do you think are the main reasons that women with disabilities do not get screened?

Is there anything someone could have told you or helped you with to convince you to get screened?

For Women Who Have Been Screened (Group B)

I'd like you to think about your female friends and relatives over age 40. If you had 1 minute to share information with one of them about going to get a breast exam and mammogram, what would you say?

What do you think are the main reasons women with disabilities do not get screened?

What would make it easier for you to go as often as recommended?

For Women Who Have Survived Breast Cancer (Group C)

I'd like you to think about your female friends and relatives over age 40. If you had 1 minute to share information with one of them about going to get a breast exam and mammogram, what would you say?

What do you think are the main reasons women with disabilities do not get screened?

What would make it easier for you to go as often as recommended?

IX Closing and Departure (10 minutes)

Groups A, B, & C

Objective: Obtain wrap-up advice from participants, thank them for attending, and provide the opportunity for them to take print information and or speak with a breast cancer expert who will be available.

I am going to step out of the room to check on your money, and will be gone for a few minutes. While I am gone, I would like you to think about any questions or concerns you have about breast exams and mammograms because I have invited someone who knows a lot about this to come back with me. She will be happy to answer anything you might like to know.

(Note: Depending on the dynamics of the group, you might invite women to write down their questions or concerns so the representative can address them without women having to identify themselves with their questions.)

When you return, signal for the breast cancer expert to join the group and introduce her. She should thank the participants and invite them to pose questions or concerns or-- if time is short-- indicate that she will remain to talk with participants afterward. You or she can offer print information for participants to take home with them.

Thank participants again, and provide departure instructions.

TOTAL TIME: Group A: 120 minutes; Group B: 120 minutes; Group C: 120 minutes

APPENDIX E
FIELD NOTE REPORTING FORMS

FIELD NOTE REPORTING FORMS

Group A

Date of Focus Group	
Location of Focus Group	
Number and Description of Participants	
Moderator Name/Phone Number	
Assistant Moderator Name/Phone Number	

Diagram of room and seating arrangements

--

Responses to Questions

Q1. Attitudes, Practices, and Experiences Regarding Health Care

Brief Summary/Key Points	Notable Quotes

Q2. Purpose of clinical breast exams and mammograms

Brief Summary/Key Points	Notable Quotes

Q3. Frequency of clinical breast exams and mammograms

Brief Summary/Key Points	Notable Quotes

Q4. Perception of Risk

Brief Summary/Key Points	Notable Quotes

Q5. Know someone with breast cancer

Brief Summary/Key Points	Notable Quotes

Q6. Reasons for not getting screened

Brief Summary/Key Points	Notable Quotes

Q7. Summary ideas and suggestions

Brief Summary/Key Points	Notable Quotes

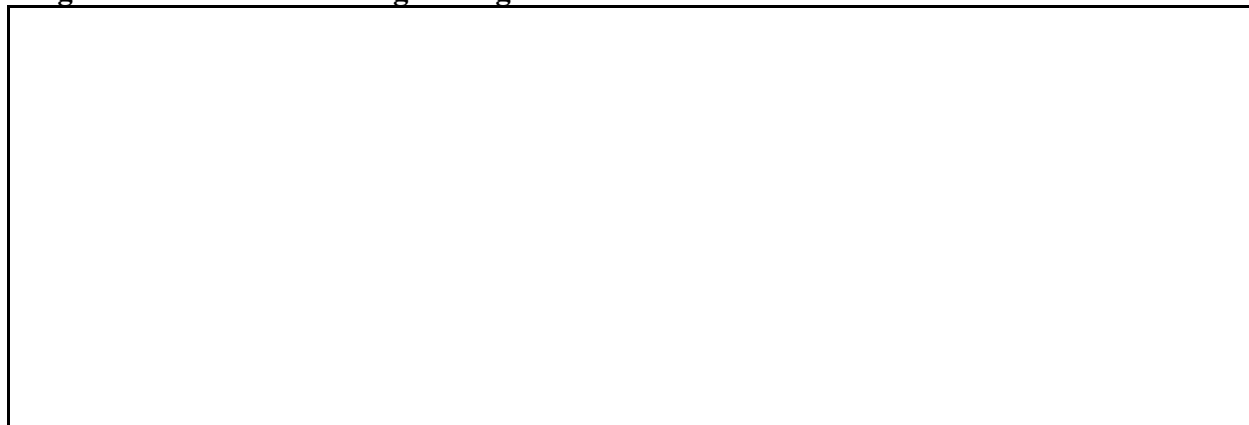
Debriefing immediately following focus group

First Impressions	
Similarities with previous groups	
Differences with previous groups	

Source: Adapted from Krueger, RA (1994). Focus groups: A practical guide for applied research. Sage Publications: London.

Group B

Date of Focus Group	
Location of Focus Group	
Number and Description of Participants	
Moderator Name/Phone Number	
Assistant Moderator Name/Phone Number	

Diagram of room and seating arrangements**Responses to Questions**

Q1. Purpose of clinical breast exams and mammograms

Brief Summary/Key Points	Notable Quotes

Q2. Frequency of clinical breast exams and mammograms

Brief Summary/Key Points	Notable Quotes

Q3. Perception of Risk

Brief Summary/Key Points	Notable Quotes

Q4. Know someone with breast cancer

Brief Summary/Key Points	Notable Quotes

Q5. Reasons for getting most recent breast exam or mammogram

Brief Summary/Key Points	Notable Quotes

Q6. Timing, logistics, and accessibility

Brief Summary/Key Points	Notable Quotes

Q7. Breast exam experience

Brief Summary/Key Points	Notable Quotes

Q8. Mammogram experience

Brief Summary/Key Points	Notable Quotes

Q9. Concerns and questions about breast exams and mammograms

Brief Summary/Key Points	Notable Quotes

Q10. Response to results of mammogram

Brief Summary/Key Points	Notable Quotes

Q11. Summary of ideas and suggestions

Brief Summary/Key Points	Notable Quotes

Debriefing immediately following focus group

First impressions	
Similarities with previous groups	
Differences with previous groups	

Source: Adapted from Krueger, RA (1994). Focus groups: A practical guide for applied research. Sage Publications: London.

Group C

Date of Focus Group	
Location of Focus Group	
Number and Description of Participants	
Moderator Name/Phone Number	
Assistant Moderator Name/Phone Number	

Diagram of room and seating arrangements**Responses to Questions**

Q1. Reasons for getting most recent breast exam or mammogram

Brief Summary/Key Points	Notable Quotes

Q2. Timing, logistics, and accessibility

Brief Summary/Key Points	Notable Quotes

Q3. Breast exam experience

Brief Summary/Key Points	Notable Quotes

Q4. Mammogram experience

Brief Summary/Key Points	Notable Quotes

Q5. Concerns and questions about breast exams and mammograms

Brief Summary/Key Points	Notable Quotes

Q6. Response to results of mammogram

Brief Summary/Key Points	Notable Quotes

Q7. Diagnosis

Brief Summary/Key Points	Notable Quotes

Q8. Treatment

Brief Summary/Key Points	Notable Quotes

Q9. Recovery

Brief Summary/Key Points	Notable Quotes

Q10. Social Support

Brief Summary/Key Points	Notable Quotes

Q11. Summary of ideas and suggestions

Brief Summary/Key Points	Notable Quotes

Debriefing immediately following focus group

First impressions	
Similarities with previous focus groups	
Differences with previous focus groups	

Source: Adapted from Krueger, RA (1994). Focus groups: A practical guide for applied research. Sage Publications: London.

APPENDIX F
INITIAL NODE TREE

INITIAL NODE TREE

Index Tree

- (1) Reason for Mammogram
 - (1 1) routine exam
 - (1 2) advised by doctor
 - (1 3) found lump
 - (1 3 1) patient
 - (1 3 2) doctor
 - (1 4) breast cancer in family
 - (1 5) advised by family member
 - (1 6) medication
 - (1 7) age
 - (1 8) menopause
 - (1 9) tenderness
 - (1 10) reminders from clinic
 - (1 11) nurse
 - (1 12) fear of cancer
 - (1 13) hormones
- (2) Barriers
 - (2 1) Physical
 - (2 1 1) equipment
 - (2 1 2) transportation
 - (2 1 3) personal assistance
 - (2 1 4) positioning
 - (2 1 5) scheduling
 - (2 1 6) isolation
 - (2 1 7) room size
 - (2 1 8) wait time
 - (2 1 9) dressing gown
 - (2 1 10) parking
 - (2 1 11) wheeling distance
 - (2 1 12) weather
 - (2 2) Attitudinal
 - (2 2 1) provider
 - (2 2 1 1) referral
 - (2 2 1 2) retarded
 - (2 2 2) patient
 - (2 2 2 1) can't get cancer
 - (2 2 2 2) other health issues
 - (2 2 2 3) fear
 - (2 2 2 4) pain or discomfort
 - (2 2 2 5) avoidance
 - (2 2 2 6) embarrassment
 - (2 2 2 7) Don't know where to go
 - (2 2 2 8) controversial message
 - (2 2 2 9) fate
 - (2 2 2 10) Better off not knowing
 - (2 2 2 11) mental stress
 - (2 2 2 12) neglect
 - (2 2 2 13) Don't think about it
 - (2 2 2 14) moved
 - (2 2 2 15) no family history
 - (2 2 2 16) efficacy

- (2 2 2 17)treatment/radiation
- (2 2 2 18)unfamiliar doctor
- (2 2 2 19)can't handle it
- (2 2 2 20)accuracy
- (2 2 2 21)cancer in family
- (2 2 2 22)stupidity
- (2 2 2 23)disfigurement
- (2 2 2 24)denial
- (2 2 2 25)lack of support
- (2 2 2 26)time/too busy
- (2 2 2 27)Taking care of others
- (2 2 2 28)lazy
- (2 2 2 29)not referred by doctor
- (2 3)Systems
 - (2 3 1)cost
 - (2 3 2)different doctor
- (3)Mammogram Experience
 - (3 1)positive
 - (3 1 1)technician/staff
 - (3 1 2)personal assistance
 - (3 2)negative
 - (3 2 1)pain
 - (3 2 2)communication
 - (3 3)results
 - (3 3 1)letter
 - (3 3 2)phone call
 - (3 3 3)in-person
 - (3 3 4)understandable
 - (3 3 5)reassuring staff
 - (3 3 6)relief
- (4)Diagnosis
 - (4 1)second opinion
 - (4 2)delayed diagnosis
 - (4 2 1)malpractice
 - (4 3)biopsy
 - (4 4)time since diagnosis
- (5)Treatment
 - (5 1)options
 - (5 2)information
- (6)Recovery
 - (6 1)function
 - (6 2)rehabilitation
- (7)Social Support
 - (7 1)family
 - (7 2)friends
 - (7 3)health professionals
 - (7 4)support groups
 - (7 5)faith community
- (8)Education
 - (8 1)provider education
 - (8 2)patient education
 - (8 2 1)source of information
 - (8 2 1 1)BC program
 - (8 2 1 2)family

- (8 2 1 3) school
- (8 2 1 4) survivor
- (8 2 1 5) disability organizations
- (8 2 1 6) public health
- (8 2 1 7) health care providers
- (8 2 1 8) American Cancer Society
- (8 2 1 9) rehab
- (8 2 2) channels
 - (8 2 2 1) TV
 - (8 2 2 2) newspapers
 - (8 2 2 3) brochures
 - (8 2 2 4) poster
 - (8 2 2 5) disability literature
 - (8 2 2 6) magazines
 - (8 2 2 7) newsletters
 - (8 2 2 8) radio
 - (8 2 2 9) bus
 - (8 2 2 10) churches
 - (8 2 2 11) web-site
- (8 3) strategies
- (9) Advice/Recommendations
 - (9 1) providers
 - (9 2) women with disabilities
 - (9 2 1) relax
 - (9 2 2) humor
 - (9 2 3) communication
 - (9 2 4) relief
 - (9 2 5) optimistic
 - (9 2 6) saves lives
 - (9 2 7) messages
 - (9 2 8) uncomfortable
 - (9 2 9) important
 - (9 2 10) acceptance
 - (9 2 11) patience
 - (9 2 12) kindness
 - (9 2 13) personal assistance
 - (9 3) system
 - (9 3 1) ADA
 - (9 3 2) manufacturers
 - (9 3 3) CIL's
 - (9 3 4) rehab
 - (9 3 5) health departments
- (10) Health care
 - (10 1) frequency
 - (10 2) delayed care
 - (10 2 1) costs
 - (10 2 2) hassles
 - (10 2 3) treated badly
- (11) Risk Factors
 - (11 1) age
 - (11 2) family history
 - (11 3) race
 - (11 4) abuse
 - (11 5) high cholesterol
 - (11 6) overweight

- (11 7)blood pressure
- (11 8)diabetes
- (11 9)smoking
- (11 10)oral contraceptives
- (11 11)caffeine
- (11 12)stroke
- (11 13)estrogen/hormones
- (11 14)exercise
- (11 15)supplements
- (11 16)environment
- (11 17>nullipary
- (11 18)diet
- (12)Group
 - (12 1)A
 - (12 2)B
 - (12 3)C
- (13)Benefits of Mammography
- (14)Q. Mammograms best way to detect
 - (14 1)yes
 - (14 2)no
 - (14 3)not sure
- (15)Q. Worry about BC
 - (15 1)yes
 - (15 2)no
 - (15 3)not sure
- (16)BSE
- (17)Q. Know someone with BC
 - (17 1)yes
 - (17 2)no
- (18)Q. BC program
 - (18 1)yes
 - (18 2)no
 - (18 3)not sure
- (19)process comments
- (20)good quotes
- (100)Case Nodes

APPENDIX G
FOCUS GROUP INFORMED CONSENT

Focus Group Informed Consent

Purpose: The Centers for Disease Control and Prevention (CDC), Baylor College of Medicine, the University of Kansas, and the University of Georgia are doing research about breast cancer screening and treatment for women with physical disabilities. We are doing this research to learn about the problems women with physical disabilities have getting breast cancer screening and treatment. You are invited to take part in this group because you know more about your health concerns than anyone. Your experiences will help us develop future health promotion programs.

Procedures: This research involves a focus group discussion which will last about two hours. For the focus group, we will ask you to pick a name other than your own to call you by. We will give you a tag with that name on it. We will ask you questions about cancer risks, health care providers, personal behaviors, and barriers to screening and treatment. You may choose not to answer any question for any reason. Say that you want to pass on the question and we will move on to the next one.

You can expect that some study staff will sit in and take notes during your focus group session. Also, we plan to record the session on audio tape. Only study staff will be able to use the tapes. The tapes are to help learn more about what is said by all of you as you discuss the topics. At the end of the study, we will erase the tapes and throw them away.

Risks/Benefits: We do not expect any risks to you from being in this focus group. While our focus group leader is very good, it is an open discussion. Issues discussed could make you feel uneasy and you could reveal private things that may be hard for you to share. You will get no direct benefit from being part of this study. But helping to carry out this research will tell us a lot about barriers to breast cancer screening and treatment among disabled women. We will use this information to design new health promotion programs. This could be of future benefit to you or someone you know.

Confidentiality: What we talk about will be kept private to the extent allowed by law. To protect your privacy, we will keep the records under a code number rather than by name. We will keep the records in locked files and only study staff will be allowed to look at them. Your name or other facts that might point to you will not appear when we present this study or publish its results.

Payment: After your focus group, we will give you \$30. This is to help repay you for the time you spent with us and the cost of coming to our study.

Right to Refuse/Withdraw: You are free to join the study or not. You may also leave the study at anytime, for any reason. If you do not join, you will not lose any services that you normally expect to get.

People to Contact: If you have any questions about how the study works, contact JoAnn Thierry, the chief study person at CDC (770) 488-7097. You may also contact Margaret Nosek at (713) 960-0505, or Glen White at (785) 864-0523. If you have any concerns about your rights in the study, contact the Deputy Associate Director for Science at CDC (800) 337-0011.

We have given you a copy of the consent form. When you sign below, it shows that you agree to be part of the study. If there is any part of this form that is not clear to you, be sure to ask

questions about it. Do not sign until you get answers to all of your questions. If you choose to join the study, sign your name on the line below.

Participant Signature Date

Print Name

Note: Form was provided in a large print format.