

Healthy Women Project 2004-2005



Community Resources for Independent Living

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- ♥ US Centers for Disease Control
- ♥ California Department of Health Services: EPIC
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Office of Disability and Health Services
- ♥ California State Department of Rehabilitation
- ♥ BHAWD - Breast Health Access for Women with Disabilities /
Alta Bates Hospital
- ♥ The Women's Foundation of California



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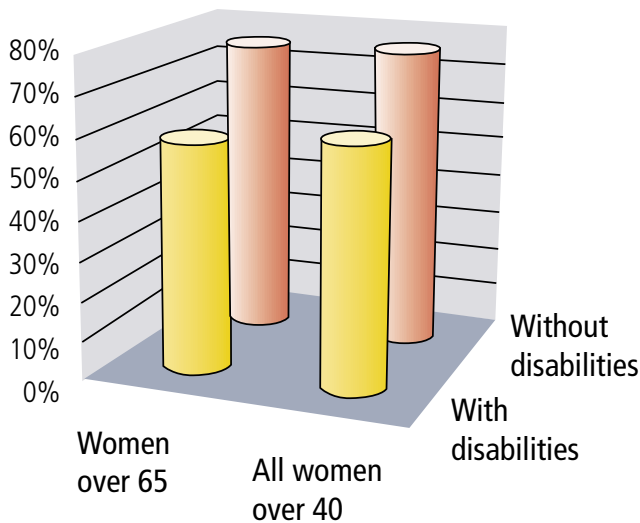
Report on the Healthy Women Project

The Purpose of the Project

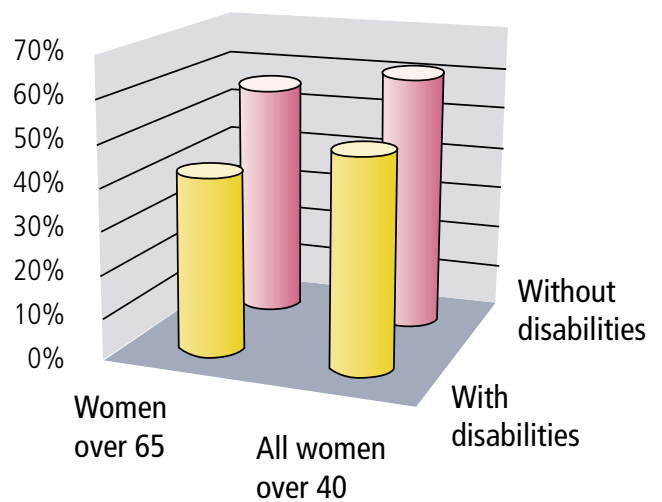
In 2003, CRIL was selected to conduct a small, qualitative study aimed at increasing screening rates for breast and cervical cancer among women with self-identified physical disabilities. Our goal was to provide women with the tools and support they need to overcome the obstacles they face to screening, while tracking which activities motivated them the most. We set out to collect data, create materials and record lessons that will contribute to the effort to understand and improve healthcare access for women with disabilities.

Breast cancer screening includes the clinical breast exam, breast self-exams, and mammography. Cervical cancer screening includes pelvic exams, Pap smears and Human Papillomavirus (HPV) testing. Breast and cervical cancer screening increases early detection, reduces mortality, and improves outcomes for people diagnosed with cancer. It is essential for women 40 or older to receive regular screenings, as breast and cervical cancer continue to be among the leading causes of death for women.

Percent of women up to date with Pap smears



Percent of women up to date with mammograms



Studies have shown women with physical disabilities are *less likely* than women without disabilities to participate in regular breast and cervical cancer screening.

Women with disabilities face many challenges to receiving screening, including:

- inadequate access to facilities and equipment
- difficulty positioning for exams
- lack of provider knowledge and insensitivity to needs
- lack of accessible transportation
- lack of adequate health insurance

Project Preparation

Once the project design was complete and approved, CRIL staff began creating materials, including surveys, consent forms, recruitment materials and a Provider Guide. CRIL staff also located and expanded upon an Accessible Transportation Guide for the region that included public and private transportation options.

We created the Provider Guide through a series of telephone interviews and site visits to measure accessibility according to strict criteria including proximity to public transportation, accessible parking, pathways, exam rooms, bathrooms and elevators, as well as accommodations for women who are deaf, have low-vision or use a service animal. Ultimately, it included 16 facilities in the region that provide mammograms and gynecological services to women with disabilities. Many have adjustable exams tables and equipment. Later, as the regional reach of the project was expanded, we created a supplement with eight additional facilities.

Everyone who enrolled in the project was given these materials. In addition, CRIL staff provided the gynecological facilities included in the Provider Guide with a copy of *Table Manners – The gynecological exam for women with developmental disabilities and other functional limitations*.

The next step was to put together the workshop curriculum and peer-counseling guides. We aimed to create educational materials that would help women understand the importance of breast and cervical cancer screening and the risks of going without them. The result was a 50-plus-page, interactive curriculum and two peer guides, each more than 150 pages long. Sources included articles, books, videos and websites, as well as interviews with other researchers and women with disabilities.

Recruitment

CRIL set out to find 80-100 participants. Our criteria: Women, 40 or older, possessing a self-identified physical disability for two or more years, who had not had a mammogram in over a year or a Pap smear in over two years.

Recruitment, which included calls to women in CRIL's database, mass mailings through local paratransit organizations, advertisements in local papers and newsletters, and trips to various health fairs and support groups, proved more difficult and time-consuming than expected. Some 360 phone calls led to 190 conversations with potential participants. About half, roughly 87, expressed interest in joining and were mailed enrollment materials. In the end, just over half of that group, 46 women, participated in the project from start to finish.

We divided the participants into three groups: the workshop group, the peer-counseling group, and the control group. All were given 'before' and 'after' surveys quizzing them on knowledge of breast and cervical cancer and prevention, attitudes towards screening and attitudes towards health care. We also gathered basic demographic data from the women.

The Interventions

14 participants served as a control group, receiving materials by mail only.

16 women participated in peer-counseling over the telephone with the project coordinator, a woman with a disability. The sessions averaged 55 minutes. After building trust and learning about each woman and her disability, the peer-counselor presented basic information on cancer, risk factors and screening guidelines. From there, the sessions were consumer-driven and tailored to the specific barriers the women believed were keeping them from getting regular screenings.

Another 16 women attended an interactive workshop, led by CRIL staff members with disabilities and a registered nurse with experience working with women with disabilities. The workshop emphasized the early detection of breast and cervical cancer through regular screenings. We presented the material in a variety of fashions, including over-heads, video clips, hand-outs and small and large group exercises.

The most popular part of the workshop was a creative learning tool created by CRIL staff to help women understand the importance of mammograms. Women created mock breasts from Play-doh and practiced finding different sized grains and beans hidden in the clay. The beans represent different sized tumors, those which can be found by your hand and those which can only be found by a mammogram.

What was the most helpful part of the workshop?

“The beans in the Play-Doh.

A picture is worth more than a thousand words.”

– Workshop participant

Both interventions were led by women with disabilities, for women with disabilities. This proved to be crucial in motivating participants. Many women commented on what a difference it made to talk with someone who truly understood what they are going through:

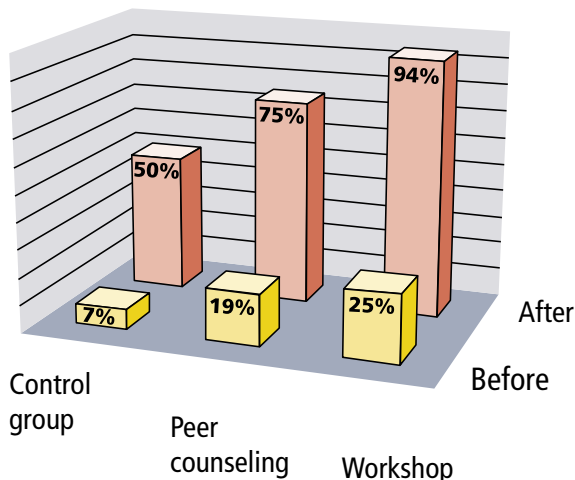
“You could see that other people are having the same problem as you, so I didn’t feel afraid to say what I had to say.” – Workshop participant

To measure the success of our interventions, we called each woman two months later to find out if she had made a screening appointment.

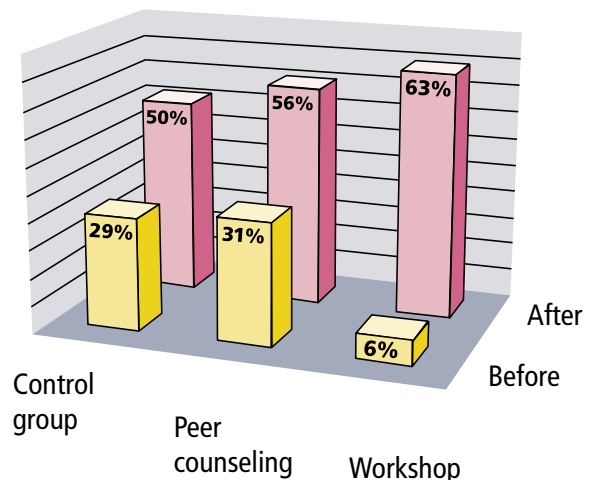
Project Findings

The project met and exceeded expectations. It showed that educating women with disabilities about cancer and encouraging them to make screening appointments is a successful venture. All three groups, including the control group, made great strides. Of the three groups, women from the workshop group proved to be most likely to seek out a screening appointment. For example, 94% of workshop participants were in compliance with mammogram screening guidelines by the end of the project, compared to 25% at the start of the project.

Percent in compliance with mammography guidelines, before and after the Healthy Women Project.



Percent in compliance with Pap smear guidelines, before and after the Healthy Women Project.



Despite the apparent difference between the workshop and the peer counseling, CRIL staff and data analysts ultimately concluded that both interventions are potentially equally effective. While the workshop proved to be highly motivational for the women who could participate, many women were not able to attend, largely due to their disability. Once we accounted for those who did peer counseling because their mobility issues prevented them from attending the workshop, the success rates of the two interventions were not statistically different.

“I just wouldn’t have done it without somebody telling me... You know you need to do it, but you need that cheerleader on the side saying, ‘Go do it.’ Now I understand a lot more what the causes of these cancers can be. I had a lot of myths and I thought I was safe because I wasn’t doing certain activities. Now I understand the risk factors better.”

– Peer-counseling participant

What’s obvious is this – both the workshops and the peer counseling are potent tools for empowering women with disabilities to overcome barriers to accessing health care. Our full report and data analysis are available to those seeking more information.

Looking to the Future

Mammograms and Pap smears are life-saving screenings that women with disabilities need to stay healthy. The Healthy Women Project shows that peer-driven education is a successful way to increase screening rates among women with physical disabilities. Having mailed all of the women a \$25 stipend for their participation, CRIL is now offering a workshop to women in the control group.

This pilot project can be easily replicated to improve the health of women with disabilities nationwide. Our complete report and user-friendly resources are available to other Independent Living Centers and community organizations seeking to increase screening rates in their communities. The data collected and lessons learned contribute to the knowledge and understanding of healthcare access and barriers for women with disabilities.

New Resources from CRIL

Provider Guide



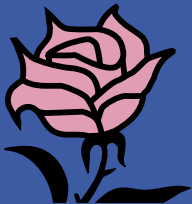
Healthy Women Project

The Healthy Women Project Provider Guide

The Provider Guide was created by CRIL staff to assist women in locating accessible places to have a mammogram or Pap smear. Staff visited each site in the guide and included only those who were accessible and willing to accommodate women with disabilities.

CRIL's guide can be used as a blue-print by organizations seeking to create similar resources for their community.

Healthy Women Workshop Curriculum



The Healthy Women Workshop Curriculum

More than 90% of workshop participants sought out a screening appointment! Now available on CD, our successful curriculum can be altered and used to put on workshops in your community. More than 50 pages in length, the curriculum is scripted so that those doing workshops as part of a study can ensure that each is the same.

The Peer Counseling Guides

CRIL staff created two peer counseling guides, one for women needing Pap smears (158 pages) and one for women needing mammograms (154 pages).

These guides can be used to encourage women with disabilities to overcome barriers related to providers, insurance, transportation, lack of knowledge, feeling depressed, afraid or overwhelmed, as well as specific disability-related barriers.

Peer Counseling Guide



The Healthy Women Project also utilized materials from the following organizations: Breast Health Access for Women with Disabilities (BHAWD), The American Cancer Society and Disability Rights Advocates.

Please visit the CRIL Healthy Women web site for more information on how to obtain these materials:

www.cril-online.org

Success Stories

Who Got Their Cancer Screenings?

She Did!

She is a busy mother and grandmother from the Tri-Valley. Despite rheumatoid arthritis and degenerative disk disease, she found the time and energy to do five breast cancer fundraising walks. When she first began the project, she was adamant about not getting a Pap smear. "I don't want to go, but you're welcome to try to convince me." What kept her from going? "I find it embarrassing, humiliating. It's the last thing I want to do. Who wants to go have a Pap smear? It's like yuck! I've done so much doctoring in the last few years of stuff that I have to go to. A Pap smear doesn't seem like something I have to do so I tend to just put it off and put it off." However, after participating in the Healthy Women Project, she happily had a change of heart. "Yes," she told us, "it motivated me to go take care of business that I needed to do...It was a good experience." How did Healthy Women Project make a difference? "Being accountable to someone and the reminder in the mail just gave me that little extra push."





She Did!

She is an independent widow with mobility issues and chronic pain due to degenerative disk disease. Her last mammogram experience had not been a good one, as the technician was not experienced handling women with disabilities. "My low income these last few years has kept me from getting screened, but now that I do have MediCal, I can follow up not only on my cancer prevention needs but all of my health needs." Fortunately, her involvement with Healthy Women Project provided "the reminder that I need to get it done.... I'm very thankful there is an organization that does care."

She Did!

She made an appointment for a mammogram almost immediately after receiving initial information from the Healthy Women Project. She had chronic pain and it had been ten years since her last mammogram. She and her doctor both found a lump in her breast, but fortunately it was not serious, and she was able to receive proper medical treatment. "The Healthy Women Project encouraged me to ask for a mammogram, and now I will ask for a Pap smear." She even told her sister about the project, and shared the things she learned while doing it.

Congratulations to these women for choosing health



She Did!

She needed and got both tests. In the past, having O.I. (a genetic “brittle bone” disorder) has been a barrier for getting tested. “The thing I fear the most is getting lifted because I’m breakable. [My provider] always asks if I have someone to come with me and lift me and I’m like screw you, no. They assume just because you’re disabled you have someone to take care of you.” However, she soon realized getting screened for these cancers was important. “This got me off the dime and that’s an important thing....The other half of me is very stubborn and very capable.” She ended up being glad she did get her mammogram.” Because [my provider] saw something on the mammogram they wanted to look at a second time, that was scary, so that will certainly keep me from skipping them in the future.” She found the self-advocacy suggestions particularly helpful. “I made the appointments the same day we talked....They gave me two appointments back to back so there was plenty of time to get on the table, like you suggested.”



She Did!

She has been diagnosed with bilateral carpal tunnel and osteoporosis. Her barriers to getting screened included feeling overwhelmed with disability issues and arranging transportation. For her, getting a mammogram was extremely important, because her sister recently battled the disease. Despite her last mammogram experience being painful, she realized, "I guess it's in the family. So I really gotta get the ball rolling and get this appointment done." She got "on the ball" and scheduled both appointments. Learning "about the percentage of women who can develop the cancer...if it's not caught on time" was her primary motivation.

The Healthy Women Project was a success thanks to the following individuals and organizations:

- ♥ All of the women with disabilities whose participation made this project possible and whose stories brought us valuable knowledge, as well as joy.
- ♥ CRIL staff and volunteers: Elizabeth Pazdral, Jackie Downing, Rose Hoban, Elisa Rossetti, Suzanne Vaughan, Angela Rodrigues, Karen Marshall, Marie Grube, Rose Coleman, Carol Raugust, and more.
- ♥ Our partner organizations and funding sources, listed previously.
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- ♥ Kaela Milosevic and Christine Jayan, Better Health Foundation
H. Stephen Kaye, UCSF Disability Statistics Center
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- ♥ Pam Dickens, Karen Luken, North Carolina Office on Disability and Health
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Thank you!

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- ♥ Grace Schoeniger, writer and editor
- ♥ Jeremy Thornton, Jeremy Thornton Design
- ♥ Additional sources listed within our materials

- ♥ **Anyone and everyone who helped but is not mentioned here**

Early Detection Can Save Your Life!

Is it any less a rose?



COMMUNITY RESOURCES FOR INDEPENDENT LIVING

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