

Despite the 20 years that have passed since the Americans with Disabilities Act and the identification of women with physical disabilities as a medically underserved population, women with physical disabilities continue to face persistent and significant barriers to women's health care.

An Initiative of INDEPENDENCE CARE SYSTEM'S
Access to Women's Health Care Program for
Women with Physical Disabilities

Funded by the Greater New York City Affiliate of
Susan G. Komen for the Cure®

**BREAST CANCER
SCREENING PROJECT
FOR WOMEN WITH
PHYSICAL DISABILITIES**

**A Report on Preliminary Findings
April 1, 2008-March 31, 2010**

ABOUT ICS

Independence Care System (ICS) operates a nonprofit Medicaid managed long-term care plan in New York City. ICS is specifically designed to assist Medicaid-eligible adults with physical disabilities to live independently and participate fully in community life.



Despite the 20 years that have passed since the Americans with Disabilities Act and the identification of women with physical disabilities as a medically underserved population, women with physical disabilities continue to face persistent and significant barriers to women's health care. Many medical facilities are not fully accessible: ramps are flimsy; doorways are too narrow; bathrooms, dressing rooms and exam rooms are too small. Mammography machines are inaccessible, and staff are often not trained to help with transfers or positioning. Many providers lack the knowledge or comfort level to treat women with physical disabilities in a sensitive, welcoming way; they may not know what questions to ask, what assistance to offer, and have preconceived ideas about physical disability.

In addition, both clinical breast exams and mammograms often require extra time and additional staff, for which the provider does not receive enhanced insurance reimbursement. If a woman's functional limitations pose a challenge to standard medical practice, there is a glaring absence of agreed upon substitute protocols, leading to inconclusive results as well as a false sense of security. Despite these barriers, some women with physical disabilities do go for mammograms, but their test results are often limited. Some women do not return for annual exams because they had such adverse experiences. Many do not go for the test at all.

Research shows that this inaccessible and unwelcoming service system has devastating consequences for women with physical disabilities and functional limitations. They receive fewer clinical breast exams and fewer mammograms than non-disabled women, with all the attendant risks, from later diagnosis to more serious illness to a greater risk of death.

THE WOMEN ICS SERVES

In existence for a decade now, Independence Care System (ICS) operates a nonprofit Medicaid managed long-term care plan in NYC. ICS was specifically designed to assist adults with physical disabilities to live independently and participate fully in community life; the agency recognized the need for increased access to breast cancer screening and early detection services for its members early in its life.

Nearly two-thirds of ICS's more than 1,600 members are women. Of those, 85% are 40 or over and therefore in need of mammograms. All are low-income; nearly three-quarters are women of color (40% Hispanic/Latino, 32% Black/African-American); and all live in the Bronx, Manhattan or Brooklyn, many in the poorest parts of the city. Of those whose educational level is known, 12% attended grades 9-11, and 10% have an eighth-grade education or less. Approximately 60% use wheelchairs. The women's disabilities cover a wide range,

“No one knows how many women with physical disabilities could have been saved if more mammography facilities were accessible to people who use wheelchairs or other mobility aides. Early detection is key to survival with this disease.”

Marilyn E. Saviola, Director,
ICS Breast Cancer Screening Project

from spinal cord injury to cerebrovascular disease, multiple sclerosis, rheumatoid arthritis, diabetes, muscular dystrophy, cerebral palsy, osteoporosis, post-polio

syndrome, and lupus; many have multiple disabilities.

In focus groups and conversations with individual women, ICS found that our members face persistent barriers posed by unavailable, inaccessible and unwelcoming mammography facilities that failed to address their special needs.

In addition, women with disabilities have functional limitations, often severe, which can have great implications for their ability to negotiate a screening mammogram.

Some women cannot move their upper bodies, hold their backs straight, lift their arms, grasp, or lean. Some cannot stand or, due to tremors or spasms, stand still. Though 85% of our female members are 40 and over and need mammograms, we learned that some had never had a mammogram, or had had such a bad experience that they never returned for follow-up care.

ICS LAUNCHES SPECIAL PROJECT

In response to these multiple barriers, ICS in April 2008 launched its Breast Cancer Screening Project for Women with Physical Disabilities. A pilot project, it was designed to create and test a model that would have as its goal increasing access and reducing barriers to breast cancer screening for women with physical disabilities.

Now in its third year of funding from the Greater NYC Affiliate of Susan G. Komen for the Cure®, ICS's Breast Cancer Screening Project has been very successful. With a staff of four (Administrative Director, Clinical Director, Nurse Educator/Clinical Assistant and Project Coordinator), the Project in its first two years (4/1/08 to 3/31/10) was able to:

- Identify two prestigious partners—New York Presbyterian Hospital-Columbia University Medical Center, a provider site of the Columbia University Breast Cancer Screening Partnership Program, and the Breast Examination Center of Harlem, a program of Memorial Sloan Kettering Cancer Center—who agreed to collaborate with the Project and provide mammography screenings.
- Provide disability awareness and sensitivity training to all staff at both mammography facilities; technical training to medical and technical staff; and ongoing consultation.
- Work with facility staff to implement innovative methods to make the screening easier (e.g., using Velcro straps and/or pillows to facilitate positioning); identify impediments to screening (e.g., motorized wheelchairs without retractable or removable armrests) and find solutions (e.g., providing a substitute chair); and gather advance intake information to facilitate the woman's exam.
- Coordinate initial screening mammograms for a total of 42 women at our partner facilities, including providing comprehensive, disability-competent, patient navigation services and a Nurse Educator/Clinical Assistant to

accompany each woman to her exam, offering support, documenting data about the screening (time required, extra help needed, etc.), and monitoring barriers to access that emerge. (Staff also arranges annual follow-up mammograms for women participating in the Project.)

- Provide information and education to the disability community—consumers, caregivers, health professionals, and policymakers—to increase awareness of the disparity in access to mammograms for women with physical disabilities, and to improve access to mammography screening and early detection services (e.g., techniques for breast self-exam), through one-to-one contacts, hands-on workshops, educational sessions, professional meetings, and printed materials.
- Establish an Advisory Committee, a multidisciplinary group of prominent stakeholders who are taking an active role in addressing the policy and practice challenges for women with physical disabilities in accessing mammograms that are emerging through the Project’s activities.

INITIAL MAMMOGRAPHY SCREENINGS: SIGNIFICANT PRELIMINARY FINDINGS

In the Project’s first year (2008/09), when 18 women received initial screening mammograms at our partner facilities, the focus was on referring women with less severe disabilities. All but one of the 18 women had good upper body strength; half were able to stand for their exams. In the second year (2009/10), 24 women with much more severe disabilities received initial screening mammograms; 11 were quadriplegic, one was paraplegic, and only four were able to stand for their exams.

Taking into account the differences in the level of disability of the women referred for initial screening mammograms in the Project’s first and second years, the Project identified the following as the most significant preliminary findings (see also chart, below):

- **Average Time for Screening.** In the first year, the average time for a screening mammogram was 19 minutes—slightly over the 15-minute standard reimbursable time. But in the second year, mammograms for women with much more severe disabilities took an average of 33 minutes, more than twice the standard reimbursable time.

	2008-2009	2009-2010
No. of women receiving initial screening mammograms	18	24
Average time in minutes for screening	19	33
No. (%) of mammograms requiring two technologists	3 (16%)	8 (33%)
No. (%) of mammograms producing only limited views	1 (5%)	8 (33%)

These numbers reflect the women receiving initial screening mammograms at our partner sites, not annual follow-up mammograms.

- **Extra Technologists.** In the first year, three women (one unable to raise her arms; two whose wheelchair arms were not removable or retractable) required two technologists in order to be properly positioned for the screening. In the second year, eight women (including three with fixed wheelchair

arms) required two technologists. Overall, women in the second year with more extensive disabilities required more time for screening mammograms and extra technologists, illustrating the need for enhanced reimbursement rates by Medicare, Medicaid and private insurers for the extra time and staff required.

- **Limited Views.** In the first year, only one woman's mammogram produced limited views, i.e., failed to image the complete breast. But in the second year, the mammograms for eight women—fully one-third of those screened—produced only limited views. The high number of limited views from mammograms performed on women with more severe disabilities is especially troubling; the portion of breast tissue not visualized—as well as a cancer—can be missed year after year. Furthermore, no best practice follow-up recommendation, such as an ultrasound or MRI, exists for a limited study mammogram. This situation illustrates practice deficits as well as design limitations of existing mammography machines.

The Project sought women who had not had a recent mammogram, who had never had one, or had a recent adverse experience. In the Project's first year, one woman had never had a mammogram. In the second year, six women had never had a mammogram, while nine had not had one for more than two years. Three of the women screened required biopsies; fortunately, no one had cancer.

LESSONS LEARNED

The following important lessons have emerged during the first two years of implementing the Breast Cancer Screening Project for Women with Physical Disabilities.

- **Identifying partner facilities to provide mammograms to women with physical disabilities poses an enormous challenge.** It took the Project six months to identify two partners, this after encountering reluctance, resistance, discrimination, and outright hostility from various facilities to the prospect of participating in such an initiative. Persistent advocacy is essential, as well as an appreciation for the real challenges that will be faced by collaborating facilities in terms of the extra time and resources required to provide breast cancer screening to women with more significant disabilities.
- **Many women with physical disabilities are especially reluctant to have mammograms; disability-competent patient navigation services and logistical assistance are critical to facilitating their exams.** Women with physical disabilities may magically believe that having one significant medical condition precludes their having another; fear that because of their disabilities they will be unable to endure the exam; or feel overburdened by multiple medical appointments. Some of the keys to screening success for women with physical disabilities are one-to-one education about the importance of mammograms, retrieving previous films for comparison, arranging transportation, requisitioning referrals from their primary care providers, and making multiple reminder phone calls.

- **Mammography center staff—particularly technologists—who are trained to be disability-competent and who are comfortable and welcoming are crucial to providing mammograms to women with physical disabilities.** Communicating information about the woman’s disability and her mobility aids to staff at the center prior to the appointment is also very important; it enables the staff to remove any existing obstructions to access, schedule a longer appointment if needed, and have additional staff available to help with positioning if needed.
- **Institutional policies can impede creative strategies for increasing access to mammograms for women with physical disabilities.** For example, positioning aides, such as Velcro straps to hold a woman’s arms up, can greatly facilitate positioning. However, because of institutional policies concerning restraints, some technologists have been reluctant to use such aids. Efforts to clarify or, if necessary, change related policies, like the creation of a special consent form, are needed.
- **Long waiting times for mammograms can be a particularly onerous burden for women with physical disabilities.** Some women have issues with incontinence, are unable to sit upright or still for a prolonged period, or are prone to severe muscle spasms. In addition, wheelchair users who travel by ambulance must arrange their transportation pick-ups at least a day in advance; extended wait times can leave the woman having to decide between leaving the facility before she is seen, or staying and delaying her pickup for hours.
- **No agreed upon best practices/protocols exist for women with physical disabilities whose mammograms produce only limited views, leaving open the possibility that a cancer is missed.** Efforts are needed (A) to work with radiologists to establish best practice procedures for women with physical disabilities who are unable to receive a complete mammogram, and (B) to explore policy options—e.g., Connecticut mandates a sonogram when a mammogram is inadequate for a woman due to dense breast tissue—for their applicability to women with physical disabilities.
- **Mammograms for women with severe physical limitations may take longer and require an additional technologist, for which the service provider is inadequately reimbursed.** This speaks to the need for an instrument to assess the degree of functional limitation that necessitates a longer appointment and/or additional assistance, and therefore, an enhanced reimbursement rate.
- **Many popularly used mammography machines are inaccessible to women with physical disabilities.** Advocates for people with disabilities have a unique opportunity right now to work with facilities to evaluate their equipment and insure accessibility; in accordance with the Patient Protection and Affordable Care Act, they will be required to comply with regulations and standards for accessible medical diagnostic equipment, to be issued by the federal government in 2012.

REPLICATING THE MODEL

ICS's Breast Cancer Screening Project for Women with Physical Disabilities has eight major elements that we believe are essential to replication of the model. The elements are:

1. A foundation of collaboration between a disability-competent organization and a provider of breast cancer screening services. The initial period of such a collaboration is very important, focusing on such matters as:

- An evaluation of the physical plant and equipment, and identification of any adjustments needed to ensure accessibility.
- Agreement about the number of women who will be referred during a specified pilot period; the level of disability (beginning with women with less severe disabilities is recommended); and the days/hours when the facility can best accommodate women with physical disabilities.
- A review of the demographic information the facility needs in advance of the appointment, including the woman's disability and the mobility aides she uses, along with the development of a form and process for submitting that information.
- Discussion of the potential use of positioning aides as appropriate, putting in place institutional practices (e.g., consent forms) to enable technologists to use such aides without concern.
- Agreement for ongoing consultation.

2. Disability awareness and sensitivity training for all mammography center staff, from front office to technologists to radiologists, prior to any referrals for screenings. Training logistics (time, location, number of sessions, staff groupings) are developed with the participation of facility staff. However, it is important to note that skepticism about the need for training is not uncommon and must be addressed. Some health care providers, understandably, believe that they are already sensitive to the needs of people with physical disabilities, though they may have had little experience providing mammograms to women with physical disabilities.

3. Disability-competent patient navigation services. In addition to providing standard patient navigation services (scheduling, support, follow up), a program focused on women with physical disabilities must address the women's special needs as well, especially negotiating with the home care agency, when necessary, for increased hours for the personal care worker so that she can accompany the woman to her mammography; arranging transportation, which must often be done by ambulette; and assisting in obtaining a primary care provider's referral for the exam and/or the woman's prior mammograms, activities that can present a special challenge to a woman with severe functional limitations.

4. A Clinical Assistant to accompany the woman on her appointment.

The Clinical Assistant helps with positioning and the use of adaptive aides, knows wheelchair mechanics, and acts as an advocate; documents data about the screening (time required, extra help needed, etc.); monitors barriers to access that emerge; and by her presence, strengthens relationships with the facility's staff, on which a successful collaboration depends. Although ICS has had a nurse in this role, other health care workers with experience caring for people with physical disabilities—such as a physical or occupational therapy aide or a specially trained home care worker—may work as well.

5. A Clinical Director to oversee the program. In addition to the Administrative Coordinator, Program Coordinator, and Nurse Educator/Clinical Assistant, the staff of ICS's Breast Cancer Screening Project also includes a Clinical Director. A consulting physician, she oversees the clinical aspects of the Project; participates in developing relationships with partner facilities and in training activities; directly educates women about breast health and how to be their own advocate in making the mammogram the best experience it can be (e.g., informing mammography center staff in advance that she is in a wheelchair, will need help dressing, etc.); reviews the findings of the mammograms and consults with women who need further diagnostic tests; interprets the data collected by the Project that supports the need for changes in policies and practices; and participates in the Project's policy-related bodies, chairing the Project's Advisory Committee and serving as a member of an ICS-sponsored, multi-disciplinary Think Tank on Health Care for Women with Physical Disabilities (see "Looking Ahead").

6. A method of recording basic data about the mammography exam.

While the ICS Breast Cancer Screening Project is not a research project, it has been useful to gather basic information about the woman and the exam (e.g., the woman's disability, mobility/movement limitations, length of the exam, number of technologists needed, positioning aides used, whether the test produced only limited views, etc.), which highlighted important policy and practice issues. In addition, the Project has conducted pre- and post-mammography screening surveys with the women referred for mammograms; they have provided valuable documentation of the woman's prior experiences with mammograms as well as information to help in evaluating the Project.

7. Tailored outreach, education and recruitment activities. Printed materials, one-to-one calls, visits to other caregivers and institutions, and educational workshops and forums can be important to identifying women with physical disabilities in need of screening mammograms and encouraging them to participate.

8. An avenue for input into policies and practices that will increase access for women with physical disabilities to mammography screening services. This can include the creation of an advisory committee to the project and/or participation in multidisciplinary, local, regional, statewide or national bodies concerned with health care service delivery to people with physical disabilities.

LOOKING AHEAD

The ICS Breast Cancer Screening Project for Women with Physical Disabilities, now in its third year, continues to refer women with physical disabilities for mammograms at our partner facilities; to gather data about their experiences; to expand the number of partner facilities—recently entering into a collaboration with Morrisania Diagnostic and Treatment Center, a South Bronx community-based facility of the NYC municipal hospital system; and to advocate for changes in policies and practices that will increase access to breast cancer screening for women with physical disabilities. Most recently, that advocacy has taken the form of the establishment of a multidisciplinary “think tank” to address the policy and practice barriers to the provision of women’s health care for women with physical disabilities, an initiative jointly created by ICS and the Hunter-Bellevue School of Nursing.

ICS looks forward to continuing to identify and reduce barriers to access to breast care for women with physical disabilities, and to further developing our service delivery model so that it can be replicated in other parts of the country.

For further information about Independence Care System’s Access to Women’s Health Care Program or the Breast Cancer Screening Project for Women with Physical Disabilities, please contact Marilyn Saviola at (212) 584-2587 or saviola@icsny.org, or Marissa Kaplan at (212) 420-6661 or mkaplan@icsny.org.

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“I was told that I couldn’t have a mammogram because of my size and the size of my wheelchair. But I have had two successful mammograms, which I never would have had without this ICS Project. Nothing suspicious was found—I was very relieved.”

Esther Jones
ICS Member



Welcome Home.

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