



Improving mammogram access for women of all abilities

Every year since its inception in 1985, October has been set aside to raise awareness about breast cancer and the important role that regular mammograms have in early detection and, consequently, in saving women's lives.

In 1992, a simple pink ribbon was introduced to the campaign, and it immediately became a symbol for breast cancer awareness, calling attention to the unique challenges women faced with this horrible disease. Over the years, Breast Cancer Awareness Month has grown to become an international observance, focused on the health of women, both those with and without the disease.

Most women, that is.

As is too often the case, individuals with disabilities, and their complex needs, are overlooked in discussions about breast cancer prevention and treatment. It's surprising to many when they learn that people with physical or mental disabilities have an added burden when it comes to chronic or acute medical issues. For a number of reasons, our society simply tends to overlook the needs of the disabled, particularly adults with disabilities.

Regarding breast cancer, a significant health disparity exists between women without disabilities and those living with a disability.

The pink ribbons and the efforts of organizations like the American Cancer Society and the Susan G. Komen organization have raised awareness of breast cancer and the life-saving impact of regular mammograms. Approximately 75 percent of women aged 50 to 74 who are without disabilities have had a screening mammogram within the past two years. Just 61 percent of women with disabilities of the same age group have had the same.

That isn't because women with disabilities have a lesser need. The opposite may, in fact be true. Women with disabilities have an increased risk of breast cancer due to such factors as early menstruation, previous chest radiation, never having had children or being overweight or obese. At the same time, fewer or inconsistent screenings increase the risk that women with disabilities

will be diagnosed at a later stage of breast cancer, leading to poorer outcomes, including increased mortality.

So, what is the solution?

Certainly, raising awareness among health care providers is an important step. It's not enough to only acknowledge that one out of every four Americans has some level of disability. Health care providers also need the training to know that routine health care or procedures are never routine for the person with disabilities.

To begin to address these questions and reduce the disparities affecting people with disabilities, the RISN Center was awarded a grant through the Inclusive Healthy Communities (IHC) grant from the Division of Disability Services, New Jersey Department of Human Services.

The Rowan Integrated Special Needs (RISN) Center has prepared an informative, 32-page booklet titled [*Women's Health and What Every Woman Should Know*](#). It provides updated and expanded information on the "Let's Talk About Health: What Every Woman Should Know" workbook that was prepared by The Arc of New Jersey in 1996. The RISN publication provides a wealth of information on women's health that will be helpful to women with intellectual and developmental disabilities (IDD).

These are some of the topics covered in the new Women's Health booklet:

- Making an appointment
- What to discuss with your provider
- The 5 P's: Permission, Privacy, Pleasure, Protection, Planning Pregnancy (or not)
- The breast exam
- The pelvic exam
- Dexa scan
- Mammograms
- Healthy relationships

The Women's Health workbook was funded in part by an Inclusive Healthy Communities (IHC) grant from the Division of Disability Services, New Jersey Department of Human Services.

Here are some tips for a successful mammogram.

When calling for a mammogram appointment, ask if the mammography facility is FDA approved. Tell the scheduling staff about your disability so the mammography staff will be better prepared to help you during the appointment.

Tell them if you:

- Use a walker, cane, wheelchair, or scooter
- Need extra time and/or help with:

- completing forms
- undressing and/or dressing
- positioning
- sitting up and/or standing
- lifting and/or moving your arms, and/or moving from your wheelchair or scooter to a chair if needed
- Have movement or other physical issues that may make the mammogram hard to do

Ask the scheduling staff if you can:

- Bring someone to the appointment to help with dressing/undressing and/or hold you during the exam
- Stay seated in your wheelchair or scooter during your mammogram if needed

Ask the scheduling staff about issues about access to and within the mammography site that might concern you, including the:

- Parking lot or garage
- Main building entrance
- Elevator
- Dressing room
- Mammography room and machine
- Rest room

To help you prepare for your exam:

- Speak with your health care provider about anti-spastic (movement) and/or pain medication before the mammogram.
- Wear a two-piece outfit with a shirt that is easy to remove.
- Do not wear deodorant, powders, or lotions on or near your breasts and underarms.
- Bring your insurance card.
- Make sure you understand your family history of breast cancer.
- Know the dates of your prior mammograms.
- Know where you received earlier mammograms and your doctor's name/address.

Improving access for mammograms for women of all abilities is our goal. When we improve access for marginalized patient populations, we can improve the overall health of our communities and we can thrive.