HEALTHACCESS
for Women with Disabilities

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Welcome to
Health Access for Women with Disabilities

by Marianne Valls

With the Monday Morning Project and Partners in Policymaking, the New Jersey Developmental Disabilities Council has taken the lead in supporting people with disabilities to advocate for themselves. Therefore, it is not surprising that the Council is funding an effort to explore and improve all aspects of health care for women with disabilities. More importantly, the Council has insisted that it be run by the people it affects most, **women with disabilities.**

A l998 report issued by the Center for Disease Control (CDC) indicated that women with disabilities are a minority within a minority. According to the report: *Women with disabilities are among the most disadvantaged groups in our society and may be at greater risk for health problems than men with disabilities or women without disabilities.*

Matters have not changed since the report. Women with disabilities, especially in the area of health care, need a voice. New Jersey found that voice in August of 1999. The Council sponsored Colleen Fraser, then Executive Director of the Progressive Center for Independent Living, and Kate Blisard, Director of the People Support Network, to attend a conference in Texas entitled "Promoting the Health and Wellness of Women with Disabilities." When they returned, they sought other women who felt that their own and others' health care was a major

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Mammography and Disability

Betty Gill encounters preventive medicine; preventive medicine encounters Betty Gill

A woman with a disability has to be wise, knowledgeable and informed to stay healthy . . .

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HEALTHACCESS
For Women With Disabilities

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Private Insurance Can Cover Preventive Screenings

by Ilise Feitshans

If a person has private insurance, either through their own employer or as a dependent spouse or dependent family member of a worker who has an employer-based insurance policy, the federal Health Insurance Portability and Accountability Act (HIPAA) protects access to insurance for health care, regardless of health status or disability. The famous part of HIPAA makes illegal "preconditions" for insurance. HIPAA states that no one who was covered by private insurance in the previous six months can be refused a new insurance policy because of "pre-existing conditions". Such conditions include long-term illness, cancer, HIV, disabilities and pregnancy. HIPAA has required many insurance companies to keep their coverage for expensive consumers who in the past had their enrollment application for insurance denied. As a result, insurance companies also have expanded their coverage to include many screening procedures and many simple diagnostic tests that were not included by insurance coverage before.

The screenings that are covered may vary with each policy, but lots of public health studies have shown that screenings avoid expensive care in emergency rooms and prevent the progress of disease that can prove very painful and very costly. So it is widely agreed that screenings are worth the time, effort and small expense they require, because in the long-term, they can save a health care system lots of money. But, no one can use the results of diagnostic tests or screenings to deny insurance coverage to someone who was covered by insurance in the months before.

The oversight for these programs comes from the Office of Inspector General, US Department of Health and Human Services in Washington, D.C. The penalties for violating HIPAA are strong, even though the complaint process takes a long time. This means that if someone refuses to give you the screenings your doctor requests, or if they use the results of screenings to deny insurance, it may violate federal law. So if you have private insurance, be sure to get all the screening you need done, knowing that your entitlement to coverage by insurance cannot be changed because of screening results— unless someone violates the federal laws.

Breast Self-Examination

by Paulette M. Eberle

Our lives hinge on learning how to perform this simple, effective examination.

"My hands are too shaky."
"I can't get my arms in the right position."
"I have limited sensation in my hands and can't feel my breasts."

These are a few of the reasons why many women with disabilities are not using the most effective tool in our arsenal against the war on breast cancer. Women with disabilities are not alone in the belief that they can't examine their own breasts; many doctors assume that there is no way that many of these women can do this examination.

There are, however, alternatives to the traditional method of self-examination. For example, observing your breasts in the same position, i.e., seated before a mirror, will allow you to notice changes from month to month. The important factor here is to look at your breasts in the same position and at the same point in your menstrual cycle every month. Any changes you note should be reported to your doctor.

If you find it difficult to hold your arm still enough to examine your breasts with your hand, try stabilizing your arm with pillows. It may also be possible to enlist the help of a female family member or trusted aid to hold your arm steady, allowing you to feel your breast. If it isn't possible for you to reach your entire breast, don't give up. Examine those parts of your breast you can reach and be aware of any changes you feel during your examinations.

For some women, self-examination may be tiring. It isn't necessary to complete the exam in one session. Examining the breast in very short sessions over the course of a week is still effective in noting any changes.

Doctors have also recommended that women examine their breasts in the shower or bath. This is particularly effective for women with limited upper body mobility. The combination of wet skin and soap makes it easier for the hand to move over the breast.

It also may be possible to have another woman assist with the exam. If this is an idea that appeals to you, it might be wise to have this person present during an exam by your doctor. The doctor, patient and 'helper' can then discuss exactly what is necessary to do an effective breast exam.

If a woman has difficulty understanding what she should be looking for, doctors and various health organizations have models that the patient can practice on. This will allow the woman to become familiar with what a lump or other abnormality might feel like. The American Cancer Society can put you in touch with someone in your area who offers this service.

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Increasing Breast Health Access for Women with Disabilities

"Research shows that, for women with disabilities, access to mammography decreases as age and the number of functional limitations increase."

A national conference was held in 1999 in Berkeley, California, entitled "Increasing Breast Health Access for Women with Disabilities." Wanda K. Jones, Deputy Assistant Secretary for Women's Health and Director of the Office on Women's Health, U.S. Department of Health and Human Services, delivered a keynote address, which we have reprinted with permission from the Office on Women's Health.

For more information, visit the national Women's Health Information Center Web site at www.4women.gov or call 800.944.WOMAN.

Dr. Jones set the tone for the conference, raising themes and issues repeated by speakers throughout the day. Among these were possible differing risk factors for breast cancer, barriers limiting access to breast health, and lack of reliable data about women with disabilities.

Access to money is a problem in breast health for women with disabilities, but "not the whole piece of the picture," Dr. Jones said.

"And architectural barriers are not the only roadblocks to breast health for women with functional limitations," she said.

Among factors that could increase the risk of breast cancer among women with disabilities, Dr. Jones cited differences in exercise and nutrition, prolonged use of medications, more frequent exposure to X-rays and differences in childbearing histories. Prospective studies could be important in determining the existence of differing risk factors, she added.

Dr. Jones called lack of data "a stumbling block to addressing issues of breast health for women with disabilities." Until this conference, Dr. Jones said, advocates for breast cancer and for women with disabilities "had not crossed paths to demand data that will benefit mutual constituents…at least until now."

"Data is what drives us," Dr. Jones said. "The problem we deal

with is invisibility. We can't assume that no data means no problem."

According to Dr. Jones, research shows that, for women with disabilities, access to mammography decreases as age and the number of functional limitations increase.

She cited a study of women over age 40 that found an 11-percent difference in mammography rates between women with no functional disabilities and those with three or more. Only 55 percent of women with one or two functional limitations and 50 percent of women with three or more disabilities had had a mammogram within the last two years.

Among women age 65 and older, the study found 57 percent of those with no functional disabilities had had a mammogram within the past two years, compared with 52 percent of women with one or two disabilities and 43 percent of those with three or more.

Statistics indicate more than 10 million women nationwide are limited by some disabling condition, Dr. Jones said. Those conditions include orthopedic problems, osteoarthritis, deafness, hearing and speech impairment, paralysis, cerebral palsy, multiple sclerosis, muscular dystrophy, spina bifida and cystic fibrosis.

Progress is being made. Efforts include work on imaging technology, such as hand-held equipment that could allow for in-home mammography. "There is the possibility in our lifetime of remote-site treatment," Dr. Jones said.

Dr. Jones emphasized the importance of raising the sensitivity of the medical community to the needs and perceptions of women with functional disabilities.

"Building partnerships and taking action at the local level are essential in working for better access to breast health for women with disabilities," Dr. Jones stressed. "Federal agencies can't do it all."

"There are some very enlightened elected officials working to solve these problems," Dr. Jones said, stressing the importance of working with those individuals to push this agenda. "We are dependent on goodwill at local levels. Programs have been cobbled together by national and state funding and through collaborations with corporations and foundations. We're going to see continued cobbling together."

"Breast Health Access for Women with Disabilities (BHAWD) is a tremendous model of a community-based solution. I know of no other community model quite like it," Dr. Jones said, emphasizing BHAWD's culture of partnership.

Issuing a challenge to women to empower themselves in striving for better access to breast health, Dr. Jones concluded by quoting poet Maya Angelou: "If one is lucky, a solitary fantasy can totally transform one million realities."

Breast Self-Examination

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> " Women with disabilities are not alone in the belief that they can't examine their own breasts; many doctors assume that there is no way that many of these women can do this examination. "

A group of women with disabilities in Nashville, Tennessee overcame their embarrassment and formed a breast examination club. These women meet once a month for the purpose of helping each other examine their breasts. At a meeting six months ago, one member noticed that a blind woman seemed to have had a change in the color of her nipple. This woman had just had a gynecological exam the previous month and nothing had been found amiss. After the change of nipple color had been noted, she called her doctor and made an appointment. He diagnosed breast cancer in a very early stage. The woman was treated successfully with radiation and no surgery was necessary.

Self-examination has been the deciding factor in a large percentage of many successfully treated breast cancers. Pride and embarrassment are powerful forces, but we shouldn't let them stop us from using this important diagnostic aid.

Mammography & Disability

Finding an accessible health care facility may be only half the battle

by Marianne Valls

There are frequent public service announcements telling women the importance of an annual mammogram. However, according to 1999 statistics in a report by the Center for Disease Control (CDC) "women with functional limitations" are less likely to have breast and cervical cancer screenings than are able-bodied women. The limited data concerning screenings that is available for women with disabilities only complicates matters.

Lack of screenings increases with age and physical limitations. "Twenty-two percent of women over 40 with no disability say they have *never* had a mammogram, compared to 29 percent of women with three or more functional limitations."

The CDC report cites several reasons for the dismal data. Many physicians refuse even to treat women with disabilities. For example, health care providers may feel that a pap test is unnecessary because the medical profession assumes that disability precludes sexual activity. Therefore, it is presumed that women with disabilities are at less risk for this type of cancer than women without disabilities are. Inaccessible equipment plays a major role in the failure of women with disabilities to obtain screening.

Betty Gill

In spite of the dire statistics and enormous physical obstacles, Betty Gill was able to obtain a mammogram, an important, and sometimes life saving, health screening. Betty uses a wheelchair as a result of quadriplegia.

It took Betty six months to find an accessible facility. When she did, only half the battle was won. Betty's physical limitations make the actual exam extremely difficult. Betty goes to Hillsborough Radiology, which she finds very accessible. Although the machines are designed for women who are standing, they can be repositioned to accommodate her.

However, because she cannot stand and is unable to move easily in her chair, she has to become a "contortionist." According to Betty, the technicians who help her must be "coordinated, resourceful and willing to work" with her.

Unfortunately, because mammograms are only scheduled on a yearly basis, one rarely has the same technician twice.

Betty is more concerned about getting an accurate mammogram. She feels this is impossible because of her disability. Betty doubts whether she ever had what she considers a "complete mammogram." She is sure her inability to stand and to position herself correctly interferes with the quality of the x-ray.

Betty knows all too well that she was lucky to find Hillsborough. She says it was a "hit or miss" situation. Her gynecologist did not even know where to send her for the exam. There is little information about accessible screening equipment and few health care providers appear to know of their existence. A woman with a disability does indeed have to be a wise, knowledgeable and an informed consumer if she is to stay healthy.

Working closely with legislators will help all women obtain accessible health care

by Anita Clavering

As a woman living with developmental disabilities, I am concerned with health care issues that affect women with disabilities. As a "Monday Morning" co-facilitator representing Middlesex County and a "Partners In Policymaking" graduate, I learned that working closely with our legislators to pass laws will help all women obtain accessible and available health care so they can live much fuller and productive lives.

After the groundbreaking Women's Health Care Summit sponsored by the NJDDC last June, I signed on to join its steering committee. My column will focus on bills and legislation of interest to women with all disabilities.

In each issue, my column will feature two or three bills which are either in the state legislature or in Congress. You will have an opportunity to work interactively while reading the column. In future issues of this newsletter, I will announce action alerts on legislation regarding health care for women with disabilities so you can take action in addressing your legislators. I will give the number of each bill, its sponsors and the status of the bill.

- Assembly Bill 802 (A802), on 1-8-02, sponsored by Assemblyman Herbert Conaway Jr., (Dist. 7) would establish in the Department Of Health And Senior Services a breast cancer education and screening initiative for low-income and minority women (appropriates $750,000. in funding.)
- A705, on 1-8-02, which provides a supplemental appropriation of $19 million from the Tobacco Settlement Fund to DHSS in an effort to support breast cancer screening services in New Jersey. Primary sponsors are Assemblywomen Loretta Weinberg (Dist.37) and Arline Friscia (Dist.19). Of the total amount, $16 million is to be allocated to hospitals for breast cancer screening and $3 million is to be used for a public awareness campaign to encourage women to be screened for breast cancer.

Further information on these bills, as well as addresses, phone numbers, and e-mails of the sponsors, can be found at www.njleg.state.nj.us.

I found there are so many bills and legislation on health care of interest to not just women, but all people with disabilities, that I honestly did not know where to begin.

Since the inaugural issue of *Health Access* is focusing on mammograms, I wanted to mention a couple of bills introduced in the legislature this session (SEE THE BOX ON THIS PAGE).

I will continue to track down and update the most vital legislation introduced to help women with disabilities obtain the accessible and available health care needed. The column may also announce or feature important health care legislation affecting not only women, but all consumers with disabilities.

In the past few years, we have urged our legislators to pass MiCASSA (Medicaid Community Attendant Services and Supports Act), which is federal legislation that will appropriate funding for services by health care aides that enable consumers with disabilities to receive health care, accommodations and other supports while living independently in their homes.

If you have suggestions for bills on health care for women with or without disabilities that should be posted, feel free to contact me at 732.727.7791 or by e-mail at AClavering@aol.com.

I hope to hear from you in the next issue!

Welcome to *Health Access for Women With Disabilities* *(continued from page 1)*

concern. These women formed the Women with Disabilities Health Care Planning Committee.

In June 2001, sixty-six women with disabilities met in Iselin, NJ to discuss the state of their health care. The title of their conference, Strategies for Change: Women with Disabilities Health Care Summit, clearly denoted their intent. The Summit focused on developing ways to improve the quality of health care for women with disabilities, increasing its availability and assuring that it is delivered by health professionals knowledgeable about and sensitive to the specific needs of women with disabilities, regardless of the nature of those disabilities.

The Summit was just the beginning. A steering committee was organized to further investigate the subject. The committee has four working groups: Media & Publications, Advocacy & Legislation, Wellness & Prevention, and Research.

This newsletter is the first product of the steering committee. We hope *Health Access for Women with Disabilities* will inform and empower you. An article describing a health issue which affected a woman with a disability, and how she dealt with it, will be a feature piece in each newsletter.

Since the 1960's, people with disabilities have been advocating for themselves. They have been successful in gaining the opportunity to lead independent lives. In many areas, they have become masters of their own fate. However, the struggle for equality is far from over. Gaining full access to health care for everyone is fundamental if the fight is to be won.

For a copy of the Summit report, contact: NJDDC, PO Box 700, Trenton NJ 08625-0700; 609.292.3745 (TDD: 609.777.3238). You can also access the report on the Council's web site: www.njddc.org. The report is also available in large print and on audiotape.

Health Access welcomes your comments and your suggestions. Send them to the above address or web site.