

SEX, COLOR, DISABILITY & HEALTH

BY
MARIANNE VALLS



Holly Wetscher (foreground), chair of the Women with Disabilities Health Care Steering Committee, with participants at the Health Mosaic Conference.

The late Congresswoman Shirley Chisholm once said she experienced more discrimination because she was a woman than because she was black. When a person is a member of two minority groups, it often is difficult to distinguish which is responsible for the discrimination one experiences.

The first mini conference, sponsored by the Women with Disabilities Health Care Steering Committee, explored health care discrimination and disparities among woman of color with disabilities.

Health Mosaic



Part of the planning prior to the conference was a survey designed by the Wellness & Prevention subcommittee. The purpose of the survey was to learn about the healthcare issues for minority women with disabilities in New Jersey.

By the start of the conference, 32 responses had been collected.

Those who said they had problems talking with their doctor attributed it to not understanding everything their doctor tells them. The most frequent response to “what would you want to learn more about” was “information on illnesses and conditions related to my race.” The feedback from the survey helped to shape the program for the event.

The “Health Mosaic” conference was the brainchild of Nicole L. Davis, a member of the Wellness & *(continued on page 2)*

*for Women
with Disabilities*

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Health Mosaic conference focuses on challenges faced by minority women with disabilities

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Prevention subcommittee. As a young woman of color, Davis feels that minority women, especially those with disabilities, “need more of a voice.” She points out that women of color are at greater risk for conditions like high blood pressure, breast cancer and heart disease. Davis hoped the mini-conference would raise awareness among them.

Forty-five women participated in Health Mosaic, held in April 29 in Trenton. After a buffet of ethnic food, Janice Ortiz, chairperson of the Wellness & Prevention subcommittee, welcomed the participants. Ortiz was impressed by the turnout, and thought the conference supplied “the ladies with some good information.”

Davis, who served as facilitator for the night, asked each participant to introduce themselves and tell why they had come. Davis then related her own story of medical discrimination. Her former physician apparently lacked the patience to deal with her decision to use a mobility device.

As Davis had hoped, the incident sparked some audience participation. Many said that condescending attitudes by physicians or other health

care professionals are the result of preconceived notions or lack of knowledge about disability rather than other minority issues.

Communication problems and lack of knowledge about disability seem to dominate the medical field. Initiatives in the state of Vermont, and here in New Jersey, are seeking to educate health care professionals in an effort to promote a better understanding about disability. Some members of the steering committee have participated

in sensitivity training for medical students at UMDNJ in Piscataway.

A PowerPoint presentation narrated by Anita Clavering gave the audience an overview of health challenges faced both by women with disabilities and other minorities.



Before the conference, participants enjoyed a buffet of ethnic foods. TOP: Carved melons by Lydia Blisard.



ABOVE: Council staff (from left) Pat Krupka, Sharian Mackins-Gist and Gail Hodges, and steering committee members Nicole Davis and Kate Blisard were ready to offer literature provided by YWCA of Trenton’s Breast Cancer Awareness Program; Burlington Co. Health Dept / Virtua Home Care - Comm Nursing Services; Heureka Center; MOBILE’s Healthy Ways program for African-Americans with disabilities; North Carolina Office on Disability & Health; Project S.A.R.A.H. (Stop Abusive Relationships At Home); PCIL (Progressive Center for Independent Living); University of Pennsylvania Health System, Tip Cards for Women of Color; and NJ Office of Minority & Multicultural Health.

Holly Wetscher, chairperson of the Women with Disabilities Health Care Steering Committee, was delighted that the women from the larger community got involved.

“My thoughts on the mini conference were that it was truly successful in that people from other community organizations participated.” Wetscher added that the subject of minority health and disability and its crossover effects ought to be studied further.

The New Jersey Coalition for Battered Women, represented at the event by Rose A. Williams, was exactly what Wetscher meant when she spoke about community involvement. Williams says she participated in the Health Mosaic to gain a better understanding of women with disabilities. Williams thought the mini-conference was beneficial and a great start towards increasing her understanding.

At the conclusion of the evening, Davis invited anyone who was interested in forming a group to further explore the issues, to sign-up with her.

Healthcare Resources

for Women with Disabilities

Beyond Summer Beach Reading

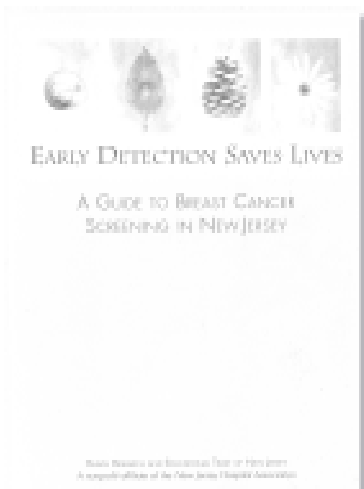
By Christine Cripps-Barker, Chair, Research Subcommittee

Developing a reference library of health care resources for women with disabilities can be a challenging task. The research committee hopes to add to the knowledge of its readers by sharing its reference “treasures.”

Here are the essentials for a reference library devoted to the healthcare needs of women with disabilities. Many are available in alternative format and/or on the web.

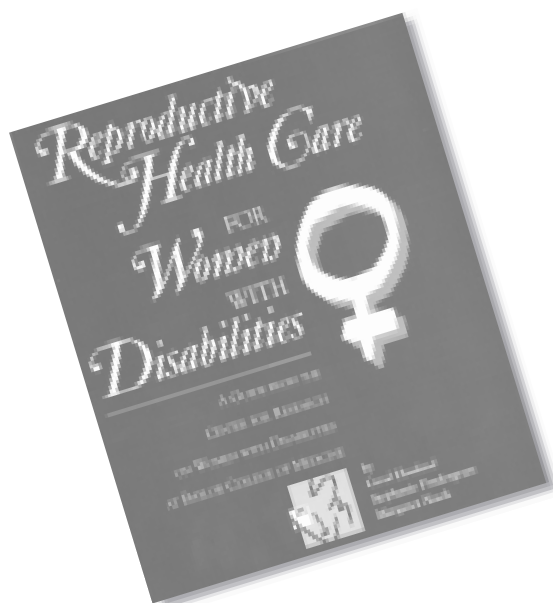
Early Detection Saves Lives: A Guide to Breast Cancer Screening in New Jersey

This guide, published by Health Research & Educational Trust of NJ, is designed to encourage more referrals by primary care physicians and better utilization of screening services, targeting high-risk populations. An index on accessibility and services is particularly helpful for women with disabilities trying to locate mammography providers. The guides are available in statewide or county-based format. For information or to request a copy, contact the Research Department at 609-275-4145.



Reproductive Health Care for Women with Disabilities

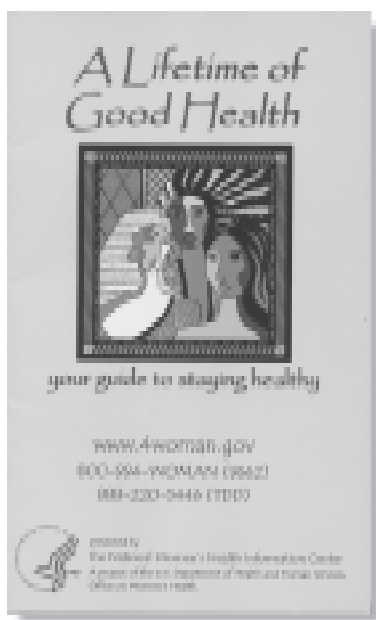
This guide published by the Center for Research on Women with Disabilities at the Baylor College of Medicine



(CROWD) is designed to inform women with disabilities about reproductive healthcare. The guide is written to educate women with disabilities on how to recognize their healthcare needs, prevention and wellness. To obtain a copy, contact CROWD at 800-44-CROWD or via the web at www.bcm.tmc.edu/crowd

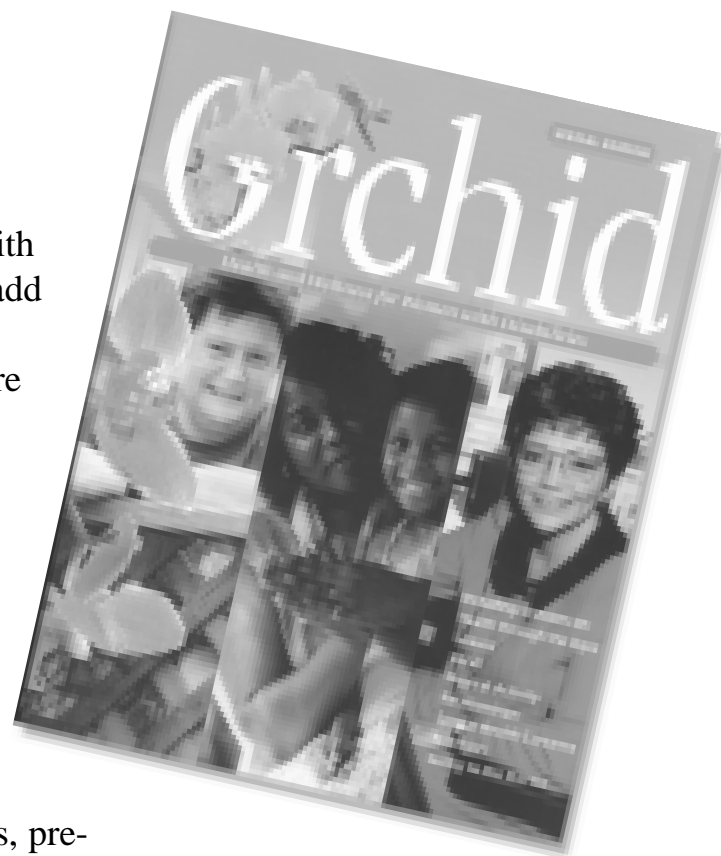
A Lifetime of Good Health: Your Guide to Staying Healthy

A project of the U.S. Department of Health and Human Services, Office on Women's Health. This 33-page booklet promotes a holistic approach throughout the “health span” by encouraging healthy behaviors, and preventing and managing the multiple health needs of women with disabilities. Copies may be obtained by calling 800-994-9662.



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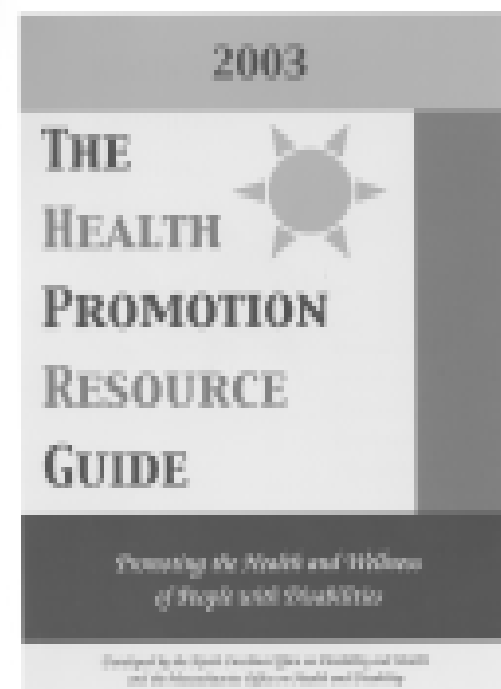
A magazine targeting health and wellness for women with disabilities. Also includes other information of interest to women with disabilities such as leisure activities, relationships, and travel. Additional copies can be ordered by email: odhpubs@mail.fpg.unc.edu or by fax:



919-966-0862. Alternative format is available in large print. Articles are available in pdf and html formats at www.fpg.unc.edu/~ncodh

The Health Promotion Resource Guide: Promoting the Health and Wellness of People with Disabilities

This guide published by the North Carolina Office on Disability and Health and the Massachusetts Office on Health and Disability was designed to increase the inclusion of people with disabilities in health promotion initiatives. The purpose of the guide is to give health educators, service providers and program planners a starting point for locating, using and adapting health promotion and wellness for



people with disabilities. Log onto www.fpg.unc.edu/~ncodh or request a copy, including alternate format, via Fax: 919-966-0862 or email: odhpubs@mail.fpg.unc.edu.

Serving Women with Disabilities: an Advocate's Guide

This guide published by the New Mexico Office of the Attorney General is intended to provide practical information on local and statewide resources for people with disabilities in New Mexico. This guide is available in large print, Braille, audio and video. Copies may be requested by calling the Office of the Victim Advocate at 505-222-9000.

Healthy Ways

A curriculum produced and designed by the Mid-Ohio Board for an Independent Living Environment (MOBILE). The goal is to assist African-Americans with disabilities in reducing the incidence of and/or complications of cardiovascular disease (CVD), cancer and diabetes through health promotion and education. For information contact **MOBILE** at 614-443-5936 or via the web at www.mobileonline.org.

Healthy Living Pocket Guide, 3rd Edition

A resource guide for African Americans whose lives are touched by HIV/AIDS and/or other life threatening illnesses. Bulk copies of the guide are available for organizations, churches, conferences and universities targeting African Americans. For information, contact 800-642-7535.

Emergency Evacuation Preparedness: Taking Responsibility for Your Safety, a Guide for People with Disabilities and Other Limitations

This guide published by June Isaacson Kailes of the Center for Disability Issues & Health Professions (CDIHP) at Western University of Health Science is designed to help people with disabili-

ties be prepared for large or small-scale emergencies. To download a copy of the guide: <http://www.cdihp.org/evacuationpdf.htm> Hard copies are available for \$24.00. Send checks payable to: CDIHP, 309 East 2nd Street, Pomona CA 91766-1854.

Women: Stay Healthy at Any Age—Checklist for Your Next Checkup

This publication (No.APPIP03-0008) is available in English and Spanish from the Agency for Healthcare Research and Quality. Top health experts from the U.S. Preventive Services Task Force suggest ways to stay healthy and prevent disease. This useful tool provides you with a checklist to talk with your doctor or nurse when you go for your next checkup and how to stay healthy no matter what your age. For information contact: Publications Clearinghouse at 800-358-9295 or www.ahrq.gov/ppip/healthywom.htm.



LEGISLATIVE UPDATE

BY ANITA CLAVERING



On March 10, 2003, I presented testimony in support of A.2759 to the Assembly Appropriations Committee on behalf of the Monday Morning Network and the Women with Disabilities Health Care Steering Committee. A.2759 will assure that a covered person with a physical disability receives medically necessary health care services from an out-of-network health care provider when there is no in-network provider reasonably close to the person's residence, is qualified by professional specialty or practice to provide those services and has experience in treating the particular physical disability, or whose physical accommodations afford convenient access to a person with a disability.

The covered person would not have to pay more for the covered services than the applicable in-network copayment, coinsurance or deductible requirements of the managed care plan.

On May 15, A 2759 passed the Assembly 77-0.

On May 19, A 2759 was referred to the Senate Health, Human Services and Senior Citizens Committee, where it remains along with companion bill S 1919, introduced by Senator Diane Allen back on September 30, 2002. Please contact your legislators in the Senate and urge them to support and move S 1919. A directory of legislators is provided at www.njleg.state.nj.us

TOWARD MEDICARE PRESCRIPTION DRUG COVERAGE

BY ANITA CLAVERING, PAT KRUPKA & SUE GOTTESMAN

This summer, Congress proposed legislation that could provide Medicare beneficiaries with limited coverage for prescription drugs. On June 27, the Senate passed S1, the Prescription Drug & Medicare Improvement Act of 2003. On the same day, the House of Representatives passed HR 1, the Medicare Prescription Drug and Modernization Act of 2003. The Senate then incorporated its bill into the House bill, added amendments and passed it on July 7.

The Senate and House then appointed conferees to resolve differences in the two versions of the bill. A detailed side-by-side comparison of the Senate and House versions of the bill is posted on the Kaiser Family Foundation web site (www.kff.org).

It is estimated that nearly six million people, 14% of all Medicare recipients, are people with disabilities under the age of 65. Disability advocates and senior citizens oppose many of the proposals in the legislation. For example, many advocates believe that the proposed plans have too many gaps in coverage and would require beneficiaries to pay too much of their prescription costs.

Both the Senate and House proposals would require beneficiaries to pay a monthly premium, an annual deductible and a certain percentage of their prescription drug costs. Medicare would pay a percent of prescription costs up to a set limit of a beneficiary's total drug costs. After the limit is met, beneficiaries would have to pay for all of their own prescription drugs until their total costs got large enough for them to qualify for catastrophic coverage. This gap in coverage, when a person's prescription drug costs exceed their basic coverage limits but have not reached a level that qualifies them for catastrophic drug cost benefits, is referred to as "the donut hole."

Many advocates also oppose provisions that require the Medicare traditional fee-for-service program to compete with private managed care

plans for the right to provide prescription coverage to beneficiaries.

The Consortium for Citizens with Disabilities (CCD) asserts that the proposed legislation will also require Medicare to operate like a private insurance company and increase its premiums to cover its costs. CCD further explains that these two aspects of the proposed legislation will have a significant negative impact on individuals with disabilities.

CCD maintains that people with disabilities often select fee-for-service plans because managed care plans do not offer access to the specialists and treatment they need. Since fee-for-service Medicare programs cover a higher percentage of people with extensive medical needs than private managed care insurers, they have much higher costs than managed care plans.

Therefore, it is likely that managed care insurers will outbid Medicare for the right to cover Medicare prescription costs. Advocates believe that people will then be forced to enroll in private managed care plans in order to access prescription drug benefits that will not be available through traditional Medicare programs. CCD argues that the proposals to privatize the Medicare delivery system will force people "to choose a provider from a closed panel of low bidders."

Another advocacy group, Families USA, agrees that the proposed competitive bidding system will cause Medicare Part B premiums to "soar" and that younger, healthier beneficiaries will leave traditional Medicare programs for private managed care plans. This pattern will perpetuate



imbalances between traditional and private Medicare insurers and will result in reductions in quality of care for people with disabilities.

Justice for All, another disability advocacy organization, says that the legislation would impose a cap on durable medical equipment and supplies for the first time, leaving many without coverage for needed equipment that is currently covered by Medicare. Advocates are urging Congress to develop proposals that will not cause patients to leave providers and will not restrict their access to a full range of treatment, medication, services and durable medical goods.

New Jersey Senators Jon Corzine and Frank Lautenberg are receptive to the need to preserve benefits. On June 27, the Senate approved an amendment they proposed that would allow individuals to participate in both federal and state pharmacy assistance programs. Corzine told *The Atlantic City Press* that he would not vote for any Medicare prescription drug program unless it will supplement, rather than replace, existing New Jersey pharmaceutical assistance programs, such as PAAD.

We will continue to follow and report on this topic in future issues of *Health Access*.

Consumer Empowerment: Educating the Health Care Provider

By Marianne Valls

Discrimination often grows out of ignorance and fear. It can be found in the strangest places. One is a medical school. The unfamiliar sometimes breeds prejudice. A little knowledge does not allay misconceptions. Indeed, book learning is often a dangerous thing.



The Women with Disabilities Health Care Steering Committee helps put a human face on the facts young medical students learn in textbooks. The New Jersey University of Medicine and Dentistry (UMDNJ) invited committee members to speak to future physicians; the participants talked about their own experiences with health care providers.

In March, I participated in a panel on community education. My intent, as always, was to encourage a view that health and disability are not mutually exclusive. In my opinion, this point often escapes the public, and especially health care providers.

My colleague, Paulette Eberle, and I were asked to discuss our “medical conditions.” I replied I did not have a “medical condition.” I have a disability. Aside from a slight problem with my blood pressure, my health is fine. Education is the key to exploding the myth that disability is a health problem.

As pointed out in a government study, “Healthy People 2000,” the assumption that poor health and disability are linked is false. Ironically, the misconception undermines the ability of an individual with a disability to lead a healthy lifestyle. This false assumption, along with others, prevents real obstacles in the environ-

ment from being addressed.

Educating health care providers early in their careers, or, indeed, even before they begin, will help eliminate structural and attitudinal barriers that exists in society. After all, good health fundamentally starts at the door to the physician’s office.

Knowledge of laws, like the Americans with Disabilities Act, which call for equal access, must be part of the medical school curriculum. Health care professionals must learn that access laws apply to them as well as of the rest of society.

Like the rest of society, the medical profession needs to acknowledge that people with disabilities can, and do, lead healthy lives. Right now the tremendous task of teaching medical providers about disability falls to individuals who deal with it on a daily basis.

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for Women with Disabilities

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