By Joanne L. Hustead, JD;
Donald W. Parsons, MD

Women's Health and Federal Policy

Historical Background

Until the latter part of the 20th century, the only women's health issues recognized by policymakers were those related to women's childbearing capacity. As a result, early debates over women's health were characterized by misguided and artificially narrow views of the policies and changes necessary to meet women's real health care needs.

From the early days of Margaret Sanger and fights over the legality of contraception to the high-pitched battle over the right to legal abortion—and to today's struggles to cure diseases like breast cancer and to raise awareness about women and heart disease—women have organized around health issues and have struggled to gain recognition of their unique health needs as well as the broad range of women's health concerns.

Expanding Recognition of Women's Health Needs

Women's greater use of health care services and their tendency to orchestrate health care for other members of the family (young and old) make nearly every pressing health care issue of the day a women's health issue as well. These issues include the need for universal health insurance coverage, the need for strong patient protections, and the need for a Medicare prescription drug benefit. As they take on these and other 21st-century battles, women and women's organizations are building on the groundbreaking efforts of the women who came before them.

The last decade of the 20th century was a time of great policy changes. Women brought their exclusion from clinical trials to the Congress and to the public and demanded—and won—inclusion. Advocates for women with breast cancer, ovarian cancer, osteoporosis, and other diseases that predominantly or exclusively affect women organized and started to change public attitudes and public policy. The Family and Medical Leave Act,[1] signed into law in 1993, recognized the expanding role of women in the workplace and the needs of women *and men* to balance their dual roles as breadwinners and caregivers. The Violence Against Women Act (VAWA)[2] was passed in 1994 and energized the public discussion around domestic violence as an important health issue.

Gender-Specific Medicine

As we enter a new era of booming medical technology, many challenges remain. One of the most important challenges, stemming from the historical exclusion of women from clinical research, is the need to better understand the biological differences between men and women and how various diseases and their treatments affect women. This clinically important area is known as "gender-specific" medicine. The right to inclusion in clinical research isn't enough; researchers need to analyze scientific and clinical data by gender if we are to gain greater insight into biological differences between the sexes.

Human Genome Research

Advances in the understanding of the human genome raise especially pressing concerns. Women have been at the forefront of the genetic revolution for many years—first because of their involvement with prenatal testing, and then with the discovery of the BRCA1 and BRCA2 genes a few years ago. These discoveries made it possible to identify some women at higher risk for breast or ovarian cancer. Greater understanding of the cause of disease brings the hope for insight into treatment and prevention, but it opens a Pandora's box of potential discrimination if information passes into the wrong hands—employers or insurers, for example. Some women have indicated a reluctance to be tested: they fear that the act of testing will itself alarm a wary employer and may lead to loss of a promotion, loss of insurability, or even loss of a job.

Recent advances by the Human Genome Project promise increased ability to predict other genetic diseases (and perhaps, ultimately, most chronic diseases) in the future. The Coalition for Genetic Fairness,[3] spearheaded by the National Partnership for Women & Families and comprising dozens of advocacy organizations concerned with known or suspected genetic diseases, is actively seeking stronger federal protection against misuse of genetic information as part of a Patients' Bill of Rights or through separate legislation. Such protection would build on the Health Insurance Portability and Accountability Act of 1996 (HIPAA),[4] which provides that employment-based group health plans cannot discriminate against present or potential policyholders on the basis of genetic information. HIPAA also provides that genetic information alone cannot be treated as a "pre-existing condition."

Privacy of Medical Information

Meanwhile, Congress continues its struggle with the question of how to guarantee the privacy of all medical information, including genetic information. Proposed regulations promulgated by the Secretary of Health and Human Services at the close of 1999[5] respond to many privacy concerns, but specific Congressional action may be needed before all parties feel a sense of trust. Most observers believe that Congressional action on comprehensive medical privacy legislation is not likely to happen this year. However, the computer revolution and an everchanging health care system that places private medical information into many hands will keep the issue in the public eye.

JOANNE L. HUSTEAD, JD, is the Director of Legal and Public Policy at the National Partnership for Women & Families. She received her law degree from the University of Pennsylvania School of Law in 1982. Her primary areas of expertise are the health care delivery/insurance system, and women's health. E-mail: jhustead@nationalpartnership.org

DONALD W. PARSONS, MD, is the Permanente Federation's Associate Executive Director for Health Policy Development. E-mail: don.parsons@kp.org

The Breast and Cervical Cancer Treatment Act

More likely to gain Congressional approval this year is an important program to provide treatment for low-income, uninsured women diagnosed with breast or cervical cancer. The Centers for Disease Control and Prevention (CDC) established a national breast and cervical cancer screening program for low-income, uninsured women in 1990,[6] but this program did not guarantee treatment for women who had positive screening test results. The Breast and Cervical Cancer Treatment Act[7] has been introduced to fill this gap by providing for Medicaid coverage through a new state option. This proposal was passed in early May by the US House of Representatives with one dissenting vote and is likely to be enacted into law this year.

The Family and Medical Leave Act

Women are the nation's primary health care consumers and caregivers. Nonetheless, many women still have an unmet need for time off from work to care for themselves or a family member or to have a child. The Family and Medical Leave Act (FMLA),[1] which provides job protection and continuous health insurance for people who need time off from work because of childbirth or adoption, family illness, or their own serious medical condition, has been embraced and applauded by employers and politicians alike. However, only businesses that employ 50 or more people are required to comply with this law. Efforts are underway to expand the scope of the FMLA to include midsized businesses (ie, those with 25 to 49 employees), expand opportunities for taking leave from work, and expand sources of funding such leave—for example, unemployment insurance and disability insurance. The federal government has issued a final regulation[8] to clarify that states can use unemployment funds for this purpose. States are also addressing this issue. This year Minnesota considered financial incentives for employers, and California, Illinois, New York, Connecticut, and New Hampshire already have authorized studies of ways to make family leave more affordable.[9]

Women's Safety Legislation

Other bills pending or proposals under consideration include a reauthorization of VAWA, and VAWA II,[10] which, among other things, would build on HIPAA by prohibiting health insurance discrimination against victims of domestic violence in more markets.[4] In addition, California Congressman Fortney (Pete) Stark has introduced legislation to establish federal standards for use of safer needles to protect the nursing and health care technician workforce (predominantly female) against needle-stick injuries.[11]

When Will Women's Health Policy Meet Women's Needs?

Many women's organizations are still working hard to bring this diverse range of issues to the attention of the public and policymakers, but much work remains to be done before women's health policy evolves to meet women's needs. With all this attention, women's health, social, environmental, and workplace concerns can no longer be ignored. ❖

Women brought their exclusion from clinical trials to the Congress and to the public and demanded—and won—inclusion.

References

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2. Violence Against Women Act (VAWA) of 1994, Pub L No. 103-322, 108 Stat 1796. (Sept 13, 1994).
3. Coalition for Genetic Fairness. http://www.nationalpartnership.org/healthcare/genetic/coalition.htm.
4. Health Insurance Portability and Accountability Act of 1996 (HIPAA), Pub L No. 104-191, 110 Stat 1936 (Aug 21, 1996). [For more information on HIPAA, visit the National Partnership's Web page (http://www.nationalpartnership.org/healthcare/hipaa/guide.htm) and read or download the HIPAA guide. HIPAA also provides some protection for victims of domestic violence from discrimination by employment-based group health plans.]
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6. Centers for Disease Control and Prevention. National Center for Chronic Disease Prevention and Health Promotion. Cancer Prevention and Control National Breast and Cervical Cancer Early Detection Program. http://www.cdc.gov/cancer/nbccedp/index.html.
7. Breast and Cervical Cancer Treatment Act of 1999, [pending], S 662, 106th Cong, 1st Sess (1999); Breast and Cervical Cancer Prevention and Treatment Act of 2000, HR 4386, 106th Cong, 2nd Sess (2000).
8. 65 Fed Reg 37210 (June 13, 2000).
9. For more information on the FMLA and state proposals to make family and medical leave more affordable, visit the National Partnership's Web page (http://www.nationalpartnership.org/workandfamily/workmain.htm).
10. Violence Against Women Act II (VAWA II), [pending] S 51, 106th Cong, 1st Sess. (1999).
11. Health Care Worker Needlestick Prevention Act, [pending] HR 1899, 106th Cong, 1st Sess (1999).