

PREVENTION & WOMEN'S HEALTH

*Making the
Health Care System More
Responsive to Women*

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DIALOGUE

WASHINGTON, DC

Foreword

This report is the first in a series of programs made possible by a grant to Grantmakers In Health (GIH) from The Commonwealth Fund to bring grantmakers together with experts in policy, practice, and research to exchange information and ideas about key health issues facing the nation.

On May 10, 1999, GIH convened a small group of grantmakers along with experts in community health, research, and government for an Issue Dialogue on prevention and women's health. Intended to both share lessons learned and stimulate new ideas, the Issue Dialogue proved to be a lively and insightful forum on the challenges and opportunities in funding projects in this area. This Issue Brief brings together key points from the day's discussion with factual information on women's health and grantmaker activities drawn from a background paper prepared for Dialogue participants.

Special thanks are due to those who participated in the Issue Dialogue but especially to presenters Martha Campbell, Karen Scott Collins, Sylvia Drew Ivie, Wanda Jones, Joan Leiman, Claire Payawal, and Carol Weisman. Other grantmakers including Diana Aranda of The San Francisco Foundation and Nancy Zions of the Jewish Healthcare Foundation provided valuable information on their organizations' portfolio of projects in women's health. Anne Schwartz of GIH's staff planned the program and wrote the background paper. Sarita Bhalotra and Dennis Beatrice contributed to an earlier draft. Mary Darby skillfully synthesized the background paper with points made at the meeting. GIH also gratefully acknowledges the support and advice of Karen Scott Collins and Brian Biles from The Commonwealth Fund in developing the program.

About GIH

Grantmakers In Health's mission is to help foundations and corporate giving programs improve the nation's health. It works to build knowledge, skills, and effectiveness of individual grantmakers and the field of health philanthropy. It also seeks to foster communication and collaboration among grantmakers and to provide links with experts who can help grantmakers shape their programs.

GIH structures its programs to anticipate changes in the nation's health and health policy and help grantmakers respond to those changes. Its Resource Center on Health Philanthropy monitors the activities of health grantmakers and synthesizes lessons learned from their work. GIH's Resource Center includes a searchable database on the priorities, grants, and initiatives of foundations and corporate giving programs working in the health field.

In addition to its Resource Center, GIH has several special initiatives including its:

- Support Center for New Health Foundations — Helping new health foundations develop effective programs, organizational structures, and operational styles
- Policy Programs — Building bridges between grantmakers and policymakers
- Partnerships for Maternal, Child and Adolescent Health — Working to foster collaborative efforts between grantmakers and the public sector to improve the health status and well-being of mothers, children, adolescents, and families.

GIH's services are designed for executives, staff, and trustees of foundations and corporate giving programs working in the health field. The organization serves the general health grantmaking community, develops targeted programs and activities for segments of this community, and provides customized services for individual funders. Specific activities include holding meetings (issue-focused forums, workshops, and large annual gatherings of grantmakers), providing education and training, tracking the field and conducting studies of health philanthropy, providing technical assistance on both programmatic and operational issues, making referrals to expert consultants, and brokering professional relationships.

Grantmakers In Health does not give grants or provide assistance in finding grants.

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Meeting Agenda

Prevention and Women's Health: Making the Health Care System More Responsive to Women

May 10, 1999

A GIH Issue Dialogue
Loews L'Enfant Plaza Hotel
Washington, DC

10:00-10:30	Welcome and Plan for the Day	1:00-2:45	Grantmaker Activities and Opportunities
10:30-11:00	Identifying the Opportunities: Overview Karen Scott Collins, <i>The Commonwealth Fund</i> Joan M. Leiman, <i>The Commonwealth Fund Commission on Women's Health</i>	2:45-3:00	Summary and Wrap-Up
11:15-12:00	Views from the Field Insights from experts in women's health about priori- ties they see around issues of prevention and women's health, featuring speakers from government, community health, and research Wanda Jones, <i>Dr.P.H., Office of Women's Health, US Department of Health and Human Services</i> Sylvia Drew Ivie, <i>T.H.E. Clinic</i> Carol S. Weisman, <i>Ph.D., University of Michigan</i>		
12:00-1:00	Lunch and informal discus- sions among participants and speakers		

Introduction

Until recently, women's health has been defined in terms of women's roles as the bearers and raisers of children. In this context, women's health programs have focused on reproductive health care and strategies to protect maternal health as a means of improving child health. But women's social and economic roles have changed, and so too have concepts about women's health. Advocates, health professionals, and experts in government and academia are now promoting a more expansive definition of women's health that looks at health issues as they affect women across the life span. This new paradigm also considers the role of gender as both a physiological and a sociological construct in how women interact with the health system, experience disease, and respond to treatment (Weisman 1997).

The changing definition of women's health makes it difficult to track what is being done to respond to women's health needs. It is also a challenge to track funding streams, because neither public nor private funding is necessarily formulated by gender. More often, programs are designed to serve people who are not served, underserved, or high risk. These populations are often made up of women by default. It is not clear, however, whether universal or gender-specific programs are more effective in reaching and serving women (Mead 1994).

As notions about women's health have evolved, the body of evidence about the importance of health promotion and disease prevention to women's health has grown. The U.S. health care system remains largely focused on delivery of medical care, but the pendulum has shifted somewhat, as reflected by the growth of public and private funding for prevention, including growth in coverage of preventive services by public and private insurers.

On May 10, 1999, Grantmakers In Health convened an Issue Dialogue on Prevention and Women's Health, in recognition both of the important role that preventive and health promotion activities play in health and of the need for women's health programs to more fully embrace these activities. Prevention was defined to encompass both primary prevention, targeted at reducing the risk of morbidity, and secondary prevention, those efforts aimed at detecting disease at its early stages in order to implement prompt and effective treatment. It was defined broadly to refer not just to the delivery of clinical preventive services but to a range of activities that can help reduce the incidence and prevalence of morbidity and mortality. These activities include:

- increasing access to health care services,
- educating women and developing incentives to promote lifestyle changes,
- empowering women to take charge of their own health, and
- using research to identify the value and cost-effectiveness of preventive services, strategies for accessing them, and approaches for changing behavior.

During the day-long Issue Dialogue, participants heard presentations from grantmakers who have made major commitments to prevention and women's health and from experts in government, community health, and research. Participants engaged in a lively open exchange of ideas, experiences, and information about what the grantmaking community can do to support and improve programming in prevention and women's health.

This Issue Brief draws on a background paper prepared for the Issue Dialogue and synthesizes the discussion at the meeting to shed light on issues related to prevention and women's health

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About 24 percent of all women smoke, and smoking has declined less among women than among men.

Nearly 40 percent of women do not exercise regularly.

More than one-quarter report being overweight.

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and explore how grantmakers can respond to them. It is divided into six sections:

- reasons that grantmakers might choose to focus on prevention and women's health;
- findings from The Commonwealth Fund 1998 Survey of Women's Health;
- how major actors in the health system, including government, employers, managed-care plans, and national voluntary organizations, are responding to women's health needs;
- examples of what grantmakers with different missions and resources are doing in the area of prevention and women's health;
- lessons learned by grantmakers who have supported programs in prevention and women's health; and
- challenges that remain and the types of strategies that grantmakers might wish to pursue.

The Case for Prevention and Women's Health

Preventable diseases impose a heavy burden on women. Some preventable diseases, such as ovarian, cervical, and breast cancers, and osteoporosis, affect women almost exclusively. Others have a disproportionate impact on women. For example, women, especially minority and low-income women, suffer disproportionately from the burden of sexually transmitted diseases (STDs), which can lead to impaired fertility, poor pregnancy outcomes, reproductive tract cancers, and HIV infection. Women are also at higher risk for arthritis, depression, and domestic violence. In addition, a growing number of funders are concerned about in utero exposure of the fetus to endocrine-disrupting chemicals. Poor women and their children are more vulnerable to this type of risk because of their higher use of plastic bottles, microwaved meals, and other disposable products, as well as their higher exposure to poor air quality and other contaminants (Rachel Pohl).

A great deal is known about the impact of individual behaviors on the risk of developing serious diseases, such as heart disease (the leading cause of death among women), hypertension, diabetes, and some cancers. These behaviors include diet, physical activity, and the use of

DEMOGRAPHIC TRENDS AMONG WOMEN

Like the general population, women as a group are aging. Currently, one in five women is over the age of 65. In 30 years, that figure will be one in four. Among the very elderly, that is, those people who are 85 and older, almost 90 percent are women. That number is expected to more than triple within 30 years.

In addition, women are an increasingly diverse group. In 30 years, as many as one in four American women will be Hispanic; one in eight will be African American; one in 11 will be Asian; and one in 100 will be American Indian or Native Alaskan. White, non-Hispanic women will make up less than 50 percent of the female population. That diversity is both a challenge and an opportunity.

WANDA JONES

tobacco, alcohol, and drugs. Even so, many women continue to engage in unhealthy lifestyles. For example, about 24 percent of all women smoke, and smoking has declined less among women than among men. Nearly 40 percent of women do not exercise regularly. More than one-quarter (27 percent) report being overweight (UCLA Center for Health Policy Research undated).

Many preventable diseases, such as heart disease and HIV/AIDS, have as profound an effect on women as they do on men, although they may differ in expression and management. For example, women are 20 percent more likely than men to die in the hospital following a heart attack and are less likely to receive life-saving drugs for a heart attack. For these conditions, prevention efforts aimed at women may need to be designed and implemented differently than for the general population. But the knowledge needed to refine these efforts may be lacking because of women's historical underrepresentation in research studies about the natural history of disease and the efficacy of various treatments (Shaffer and Corish 1998).

Women have poor access to preventive health services. Data from the 1991 National Health Interview Survey indicate that women do not take preventive health measures to protect against serious illness, and they do not receive screening for treatable diseases. In that survey, 40 percent of women over the age of 40 had not received a clinical breast exam in the past two years and 43 percent of women over the age of 18 had not received a Pap test in the past year (Women's Primary Care in Managed Care 1997). These findings were confirmed in *The Commonwealth Fund 1993 Survey of Women's Health*, which also identified the major factors affecting women's receipt of preventive services as insurance coverage, having a regular source of care, financial barriers, minority status, and age.

Because women tend to make health care decisions for their families — including elderly parents and in-laws, as well as children and husbands — preventive strategies focusing on women may have spillover effects.

Closing the gaps between the known benefits of prevention and the number of women actually engaging in preventive strategies is a challenge to funders concerned about improving the nation's health. The following section discusses new data from a 1998 survey of women's health that further underscore the importance of closing these gaps.

New Data on Women's Health: Findings From a 1998 Survey

In 1993, The Commonwealth Fund established the Commission on Women's Health, a five-year initiative charged with increasing public awareness of women's health issues and identifying opportunities for improving women's health and quality of life. The Fund began the Commission's work with *The Commonwealth Fund 1993 Survey of Women's Health*, a national survey of 2,525 women and 1,000 men that yielded baseline data and new information about significant health concerns. This survey offers unique insights into the problems faced by women in terms of morbidity and mortality, accessing and utilizing care, and susceptibility to many preventable conditions.

A follow-up survey was conducted in 1998 with co-funding from the Jewish Healthcare Foundation. Released in May 1999, the follow-up survey questioned 2,850 women and 1,500 men on topics such as access to care, preventive

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health behaviors and counseling, violence and abuse, family caregiving responsibilities, mental health, and experiences with managed care. African American, Hispanic, and Asian American women were oversampled.

Overall, findings from *The Commonwealth Fund 1998 Survey of Women's Health* tell a mixed story about progress in women's health. During the five years since the first survey, women became more knowledgeable about many health-related issues, and some took steps to promote healthier and more productive lives. However, progress has been extremely uneven, occurring mostly among women with higher levels of income and education. Generally, lower-income women and those with less education lag far behind. Violence persists as a significant factor in the lives of women, the survey found, and lifetime rates of violent and abusive events are disturbingly high. In addition, despite a booming economy, more women were uninsured in 1998 than five years previously, raising barriers to accessing health care services.

The 1998 survey generated findings in several major areas, including:

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Preventive Care and Health-Related Behaviors. Generally, receipt of preventive services has changed little since 1993, despite recent emphasis on the importance of these services. Roughly half to two-thirds of women said they had received preventive care in the past year. But for certain services, such as Pap tests, nearly one of five women had not received preventive care in the past five years. Most significantly, lower-income and less educated women were less likely than higher-income, more educated women to receive regular preventive services. For example, only half of low-income women received a Pap test or mammogram in the past year, compared to three-quarters or more of higher-income women. In addition, smoking rates have remained at 1993 levels, with rates notably higher among lower-income women.

The survey also identified variations in preventive services across racial and ethnic groups. For example, among women age 50 and older, mammography rates increased from 55 percent to 61 percent. This increase was particularly pronounced among Hispanic and African American women. On the other hand, Asian American women had very low rates of preventive services across the board. Less than half had received any kind of preventive service in the past year.

Women seem to be taking greater control of their health-related behaviors. Women's exercise rates are up, and familiarity with osteoporosis and use of calcium supplements has increased since 1993. Again, however, this progress has been greatest among upper-income and college-educated women, with lower-income women far behind.

Violence. Reported rates of violence and abuse among women are disturbingly high, crossing economic, ethnic, and geographic lines. Nearly two of five women (39 percent) reported incidents of violence or abuse in their lifetime. About one-third said they had experienced domestic abuse, physical abuse at the hands of a boyfriend or spouse at some point in their lifetime. Twenty percent said they were raped or sexually assaulted, and 16 percent had experienced either physical or sexual abuse. Childhood abuse affected one of six women.

The survey also showed the corrosive effects of women's experiences with violence and abuse. For example, half of women who had experienced any type of violence or abuse reported high levels of depressive symptoms, compared with one-third of women with no history of abuse. Women with a history of childhood abuse, rape, or sexual assault were significantly more likely to have been diagnosed with anxiety or depression within the past five years. Women who had been exposed to violence were more

likely to report they were in fair or poor health and had higher rates of disability. They were also more likely to engage in unhealthy behaviors, such as smoking, possibly to cope with violence.

Health Status and Coverage. A strong negative pattern emerges when comparing women's health status across income groups: The lower a woman's family income, the greater her risk for physical and mental health problems. Lower-income women were at particularly high risk for chronic health problems. Nearly half of women in the lowest-income group said they had been diagnosed with a chronic disease, compared with a quarter of the women in the highest-income group surveyed. Low-income women were also at higher risk for having a disability that limited their work or daily activities.

At the same time, lower-income women were more likely to have problems getting health care when needed and to lack basic primary care. They were more than twice as likely as higher-income women to report recent problems with getting care, seeing a specialist, or having a prescription filled because of cost. Among all women ages 18 to 64, nearly one of four was either uninsured (18 percent) or was currently insured but had spent a time without health insurance in the past year (8 percent). In 1993, 14 percent of working-age women reported that they were uninsured. The largest increases in uninsured rates occurred among Hispanic women under age 65.

Caregiving. Women, more than men, fill the role of caring for sick or disabled relatives. About 9 percent – or 9 million women – said that they were currently providing extended care for a sick relative. Caregiving responsibilities appear to fall on women uniformly, regardless of income, race, or marital status. The extent of those responsibilities, however, varies according to income. Lower-income women were more likely to provide the majority of care

for their sick relatives. Half of lower-income women provided 20 hours or more of care per week, compared with 29 percent of higher-income women. The survey also found that the demands of caregiving may take a toll on caregivers' health – yet, women caregivers were also twice as likely to report problems getting the health care they need for themselves.

In summary, The Commonwealth Fund data demonstrate that although some strides have been made in advancing women's health, particularly in increasing women's awareness of health-related issues and their active participation in healthier activities and behaviors, a great deal of work remains to be done. Virtually all progress has occurred among higher-income, more highly educated women; the picture for lower-income and less educated women is much bleaker. Violence remains a pervasive factor in the lives of women in all socioeconomic backgrounds and its effects can be both lasting and devastating. More women are uninsured than they were in 1993; as a result, they are facing more barriers to care. Again, lower-income women are experiencing the brunt of these problems. Finally, the impact of caregiving responsibilities on women is an emerging issue that bears further investigation.

The Health System's Response to Women's Health Care Needs

Following is an overview of activities that different actors in the health care system are undertaking to respond to women's health care needs. The programs described address several issues:

- women's ignorance of the need to adopt prevention strategies,

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In 1990, the U.S. Congress enacted the National Breast and Cervical Cancer Early Detection Act, a \$160 million program designed primarily to support states in providing screening services to women with no other source of payment.

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- coverage of and access to clinical preventive services,
- patient and provider compliance with strategies known to be effective in promoting health,
- the health system's traditional orientation toward curative rather than preventive medicine, and
- the longstanding bias in research priorities and designs.

The Federal Government

The federal government plays a prominent role in women's health. It is a major payer for health services through Medicare, Medicaid, the Federal Employees Health Benefits Program, and TRICARE, the health care program of the Department of Defense (formerly known as CHAMPUS). Other federal agencies, such as the Departments of Agriculture, Housing and Urban Development, and Defense, have also taken on roles in informing, educating, and providing direct services to women. In addition, the federal government is a substantial source of grant funding in areas of importance to women, including public health, biomedical and health services

research, and direct delivery of services for special populations and specific health conditions.

Overall, direct federal spending on women's health issues (both services and research) is an estimated \$51.4 billion for fiscal year 1999 (Improving Women's Health 1999). The federal government also exerts a strong influence on women's health care, because its recommendations and funding requirements affect how care is delivered and how states and local government set their priorities.

Virtually every agency of the U.S. Department of Health and Human Services (HHS) is engaged in activities that could fall under the umbrella of women's health. Following is a description of several major federal initiatives relevant to prevention and women's health. In addition to supporting many categorical programs addressing women's health issues, HHS has established 18 National Centers of Excellence in Women's Health to serve as models for improving women's health care. These centers are integrating health care services, research, public education, and health professions education.

HEDIS PANEL WORKS TO DEVELOP MEASURES OF WOMEN'S HEALTH

What gets measured tends to get managed. That's why it is so important to develop nationally recognized indicators and measures of women's health. The Women's Health Measurement Advisory Panel (MAP) of the National Committee for Quality Assurance (NCQA) is doing just that. NCQA is a not-for-profit organization that accredits managed-care plans and is responsible for maintaining and updating measures in HEDIS, the Health Plan Employer Data and Information Set. The Women's Health MAP was established to recommend additional quality indicators for HEDIS that target women's health concerns.

To date, the Women's Health MAP has developed a new measure for HEDIS that will focus on the management of menopause, specifically the receipt of counseling by women in mid-life about their options for how to cope with hormonal changes associated with menopause. The Commonwealth Fund's 1998 Survey of Women's Health suggests that little more than one-third of women receive menopause counseling services. The Women's Health MAP has also approved a screening measure for chlamydia in younger women. Other measures under consideration include screening for osteoporosis in women who have had a bone fracture and prevention of unintended pregnancies, which will also focus on receipt of family planning counseling within health plans.

CAROL WEISMAN

Delivery of Clinical Preventive Services

Federal funds support direct delivery of preventive services to women through grants to community health centers, the Maternal and Child Health Block Grant, the Preventive Services Block Grant, the Indian Health Service, and numerous other categorical programs. For example, in 1990, the U.S. Congress enacted the National Breast and Cervical Cancer Early Detection Act, a \$160 million program designed primarily to support states in providing screening services to women with no other source of payment. The program is administered by the U.S. Centers for Disease Control and Prevention (CDC). To date, it has screened 1.2 million women, diagnosing more than 4,100 cases of breast cancer and 365 invasive cervical cancers, as well as detecting 29,000 cases of abnormal cervical cells. Current funding permits the program to reach only about 12 percent to 15 percent of all eligible women between the ages of 40 and 65 (Perez 1998). Moreover, current program rules bar use of funds for treatment.

The federal Medicare program is also an important source of preventive care for older women. Services covered by the program include vaccination against influenza, hepatitis B, and pneumococcal infection; screening mammography; screening for colorectal cancer; Pap smears; and measurement of bone density. Some managed-care plans may offer Medicare beneficiaries additional preventive services. The Health Care Financing Administration (HCFA) recognizes that these services are underused, however, and is studying ways to enhance the effectiveness of prevention initiatives. Under its Healthy Aging Project, the agency has contracted with RAND to:

- gather evidence on strategies to reduce behavioral risk factors, such as smoking and physical inactivity;

- test promising interventions with Medicare beneficiaries in both managed-care and fee-for-service settings; and
- identify ways to promote the use of Medicare-covered clinical preventive and screening services by providers.

Health Promotion

HHS is engaged in several public education campaigns that emphasize the importance of prevention and treatment of conditions affecting women. These include:

- A national program to educate women and girls about osteoporosis, with special emphasis on girls between 9 and 18 years, the prime age for bone development.
- Girl Power!, a campaign designed to provide girls ages 9 to 14 with the support and encouragement they need to build self-esteem. Materials emphasize skill-building, academics, arts, sports, and other positive activities that help girls develop self-confidence and make healthy decisions. For example, the campaign is working with the Girl Scouts of America to create a new anti-smoking merit badge.
- For Your Heart, a campaign on prevention and treatment of heart disease and stroke.

A major focus of the federal government's Healthy People 2010 agenda, now under development, is to eliminate disparities in health and health status among different populations.

Draft objectives targeting women include:

- increasing from 31 percent to 60 percent the number of pregnant women who quit smoking;
- reducing the rate of hip fracture in older women from 1,000 per 100,000 women to 800 per 100,000;

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- reducing from 44 percent to 25 percent the share of women who die within one year after a heart attack; and
- increasing the percentage of women over 40 who have had a breast exam and mammogram within the preceding two years.
- clinicians' lack of willingness to provide services, due either to lack of knowledge or time; and
- lack of willingness among clinical office staff to focus on delivery and follow-up of preventive services.

Experience shows that the health objectives set in Healthy People 2000 influence policy and practice at the national, state, and local levels. Tracking the impact of these objectives depends on how well they can be measured. Although the federal government collects a great deal of health-related data, it is not enough to accurately measure many of the specified objectives. Healthy People 2000 contained more than 300 objectives; the draft for Healthy People 2010 has nearly double that number of objectives. Ultimately, HHS may opt to develop a set of 10 to 20 leading indicators to monitor the nation's health and report regularly on health outcomes and the use of targeted services.

The release of Healthy People 2010 in January 2000 should provide opportunities for partnerships at many levels between government and private organizations, including foundations, to address the new objectives. Areas of opportunity include access to screening services for Medicare and Medicaid beneficiaries, different service delivery models, patient and physician awareness and education, and gaps in information that women from various racial and ethnic groups need to make sound health care decisions (Wanda Jones).

Influencing Clinical Practice

The Agency for Health Care Policy and Research (AHCPR) has undertaken a national research-based initiative to increase the appropriate use of clinical preventive services. Put Prevention into Practice (PIIP) targets three types of barriers to obtaining care:

- gaps in patients' understanding and concerns about costs and inconvenience;

Publications and guides have been developed to target patients, providers, and office staff and overcome these barriers. These materials include an adult personal health guide, preventive care flow sheets that illustrate timely and preventive services, patient reminder postcards, waiting room posters, and posters for preventive care timelines.

The Health Resources and Services Administration (HRSA), an important source of grant funding for health professions education, is working to increase the integration of women's health issues in professional training and to increase women's participation in the health care work force. Activities include:

- developing and disseminating information and educational models;
- collaborating with national professional organizations to develop partnerships between medical schools and community organizations around adolescent pregnancy prevention;
- demonstrating successful models for recruiting, retaining, and graduating women (particularly those from racial and ethnic minorities) from health professions schools; and
- using faculty loan repayment and professional development programs to increase the participation of women in leadership positions in health education, practice, research, and administration.

Biomedical and Health Services Research

AHCPR has a health services research agenda that focuses on women's health. Projects address the areas of reproductive care, the cost-effectiveness of clinical preventive services,

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The National Institutes of Health (NIH) dedicates about 14 percent of its research budget to women's health issues, largely through its Office of Research on Women's Health.

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hysterectomy, breast and cervical cancers, heart disease, pelvic inflammatory disease, urinary incontinence, depression, long-term care, and provider training to recognize and treat domestic violence. AHCPR also supports studies of the differences in the health care costs and access to care experienced by men and women.

The National Institutes of Health (NIH) dedicates about 14 percent of its research budget to women's health issues, largely through its Office of Research on Women's Health, which was created in 1993 to respond to institutional neglect of women's issues by the major federal research agencies. Its mandate has three components:

- strengthening research into diseases, disorders, and conditions that affect women and establishing an NIH research agenda on women's health issues;
- ensuring that women are appropriately represented in biomedical and biobehavioral research studies supported by NIH, especially clinical trials; and
- increasing the number of women in biomedical careers and facilitating their advancement and promotion.

NIH is also conducting the Women's Health Initiative (WHI), one of the largest U.S. prevention studies ever, focusing on the major causes of death, disability, and frailty in postmenopausal women. Through a randomized clinical trial of three interventions (hormone replacement therapy, dietary modification, and calcium/vitamin D supplementation) and an observational study, the WHI will provide scientific information on preventive strategies and risk factors for coronary heart disease, breast and colon cancer, and osteoporosis. A total of 164,500 postmenopausal women will be recruited from 40 clinical centers nationwide and will be followed for up to 15 years.

A community prevention study is also being conducted as part of the WHI under a collaborative arrangement between NIH and the CDC's University-based Prevention Research Centers. Each of the 12 projects funded under this agreement will provide research dissemination and translation of findings into community interventions. For example, researchers at The Johns Hopkins University are considering how to reduce the risk of cardiovascular disease among African American women.

The Food and Drug Administration (FDA) also conducts research on women's health issues as they pertain to development, approval, and use of drugs. Through its Office of Women's Health, the FDA has funded more than 50 scientific projects totaling more than \$6 million, including research related to breast and ovarian cancer, women and HIV, women and cardiovascular disease, osteoporosis, breast implant safety, the effects of estrogen, and women and autoimmune disease. FDA has plans underway to conduct the largest-ever clinical trial of two drugs that are intended to reduce breast cancer risk, tamoxifen and raloxifene. This study will include more than 20,000 postmenopausal women.

Data Collection

There is a critical need for reliable, comprehensive data to support efforts to track and improve women's health. HHS collects huge amounts of data, of which about one-quarter to one-half are analyzed and reported on regularly for programmatic purposes. HHS's National Center for Health Statistics is the largest repository of public-use health data sets.

One data collection initiative that could be tapped for research into women's health is the National Health and Nutrition Examination Survey. This is the most comprehensive, complete interview of physiologic and biological

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measures of health, and involves between 10,000 and 20,000 people. Another ongoing study, the federal Medical Expenditure Panel Survey (MEPS) conducted by AHCPH, contains extensive information about health insurance, access to health care, and utilization of health services, including preventive services (Carol Weisman).

Data from these and other federal sources may be of particular interest to researchers at academic health centers or schools of public health who look to federal data sets to identify issues and analyze policy alternatives. For example, the Dole Foundation, which focuses on disability grantmaking, awarded a \$25,000 grant that involved working with HHS to mine data sets for information specific to disability. This highly productive partnership unearthed unique and important information on disability (Jeanne Argoff).

Outreach

In addition, the National Women's Health Information Center is the clearinghouse for all federal health information on women. The toll-free number for the center is 1-800-994-woman. The center is also on the World Wide Web at <<www.4woman.gov>>. The web site has pages for African American women and for Hispanic women (in Spanish). Pages for Asian/Pacific Islander, disabled, and Native American women are under development. HHS is trying to reach out to non-white, older women in particular, and to develop appropriate messages in media that are responsive and sensitive to the needs of women (Wanda Jones).

State Governments

State activities relevant to women's health fall into three groupings:

- categorical programs, which are largely funded through federal discretionary grant programs and block grants, such as the Preventive Services Block Grant and the Maternal and Child Health Block Grant,

- Medicaid, the joint federal-state health insurance program for low-income families, and
- regulation of commercial insurers.

As many as 11 states have established offices of women's health, usually through legislation or executive order (Wanda Jones). Other states do not have specific women's health offices but designate staff within the health department to focus on women's issues. Their work is primarily targeted at coordinating efforts to improve women's health across categorical programs and is often unfunded (Health and Medicine Policy Research Group 1997).

Medicaid programs are an important source of insurance coverage for more than 11 million low-income women. Medicaid coverage for preventive services varies from state to state, in terms of both eligibility criteria and payment rates. In 1992, all states covered Pap smears and 41 covered screening mammography (Moore 1992). Managed-care plans may cover additional preventive services for their Medicaid enrollees, although data for these plans are not available.

States have also used insurance mandates to promote women's health. Of particular note are laws prohibiting so-called "drive-through" labor and deliveries. Only a handful of state mandates have focused on issues of specific concern to women. For example, only one state (Maryland) has enacted legislation mandating coverage of contraceptives, and two states (Georgia and Kentucky) have enacted osteoporosis diagnosis mandates (Kaiser 1998).

Employers

Currently, women account for almost half of the nation's workforce; that proportion is expected to rise to 63 percent in the next decade. The anticipated impact of this trend is forcing many employers to re-examine their health care benefits, work site programs, and

policies. A 1996 survey of large employers by the Washington Business Group on Health found that most employer-offered health insurance plans covered Pap smears, mammograms, and clinical breast exams. About two-thirds offered routine screening for high cholesterol, diabetes, colorectal cancer, and rubella. Relatively few, however, covered other types of preventive screening important to women, such as depression, bone density, and family violence. Health promotion programs were also less frequently offered than preventive screening for breast and cervical cancer; only about half of employer-sponsored plans offered programs in smoking cessation or nutrition, or provided information on sexually transmitted diseases (Muchnick-Baku 1997).

Managed-Care Plans

Managed-care plans traditionally have provided more extensive coverage of preventive care services, such as blood pressure checks, mammograms, Pap tests, and clinical breast exams, than traditional fee-for-service insurance. This tendency may reflect the managed-care industry's greater willingness to distribute educational materials, disseminate guidelines to providers, encourage women to use screening services, implement community outreach efforts, and engage in other activities to encourage preven-

tive care use (Women's Primary Care in Managed Care 1997). Even so, managed-care plans must still take additional steps to ensure that providers and patients comply with preventive care guidelines.

Several initiatives are underway to improve plans' performance in meeting women's health care needs. Since 1997, the National Committee for Quality Assurance (NCQA) has been working to identify and develop performance measures important to women's health for inclusion in the Health Plan Employer Data and Information Set (HEDIS). HEDIS currently measures breast and cervical cancer screening, as well as several aspects of obstetrical care, including receipt of prenatal care in the first trimester and postpartum care. Discussions are underway concerning development of measures in other priority areas, including calcium intake, counseling related to osteoporosis, birth control counseling, screening postpartum women for depression, screening for violence, unintended pregnancies, and counseling for hormone replacement therapy. Another potentially useful data set is NCQA's Quality Compass, which includes HEDIS indicators and member satisfaction variables that could be analyzed for gender differences (Carol Weisman).

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WHAT MAKES WOMEN SATISFIED CONSUMERS OF HEALTH CARE SERVICES?

The U.S. Department of Health and Human Services (HHS) is investigating how women perceive health care quality through a pilot project with six National Centers of Excellence in Women's Health. Project researchers conducted focus groups of adult women, stratified by age and ethnicity, who were asked to comment on the value of health care services and what their ideal health care would be like. Out of that project, a set of measures was developed to assess women's satisfaction with primary care services. The indicators are now being tested.

CAROL WEISMAN

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Overall, private philanthropy spent about \$152 million on health programs for women and girls in 1997.

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Research commissioned by The Commonwealth Fund (Heiser and St. Peter, (1997) reported on best practices used by managed-care plans to improve the delivery of breast and cervical cancer screening. These included patient reminder systems, provider reminders, performance feedback to providers, financial incentives for providers, and office staff reminders and procedures.

National Voluntary Organizations

A number of national voluntary organizations focus on women's health issues with missions affecting policy, practice, and research. For example, the National Asian Women's Health Organization (NAWHO) has mounted major initiatives focusing on public education and advocacy programs for depression, breast and cervical cancer, reproductive health, smoking, diabetes, heart disease, and leadership development. A major focus of NAWHO's work is empowering Asian American women to change the limiting circumstances that have affected their health and well-being. National conferences are a focal point for developing an Asian American women's health agenda and changing the way society views and treats their concerns.

Other national voluntary organizations that focus on specific racial or ethnic groups include the National Black Women's Health Project and the National Latina Health Organization. Among the other organizations addressing women's health issues is the Society for the Advancement of Women's Health Research, which has a multi-pronged agenda that includes:

- increasing funding for women's health research,
- working to include women in clinical trials,
- funding research on gender differences on various aspects of smoking,
- confidentiality with respect to medical records,

- improving research and guidelines for women at high risk for breast cancer, and
- expediting availability of technological advances for women's health.

Grantmaker Activities

Relatively few health grantmakers focus their programs on women, although many support organizations and projects whose clientele happens to be predominately female. Overall, private philanthropy spent about \$152 million on health programs for women and girls in 1997. This accounts for about 11 percent of philanthropic spending on health (unpublished data from the Foundation Center). Of this amount, about half (\$73.9 million) went to reproductive health care. It is unclear how much of this money was spent on preventive care.

Following is a description of work by three foundations: The Commonwealth Fund, the James Irvine Foundation, and the Bristol-Myers Squibb Foundation. These foundations all made presentations at the May 10th Issue Dialogue. Activities by other grantmakers in the area of women's health are highlighted as well, according to their funding strategies. This listing is not exhaustive but is intended to illustrate the diversity of approaches that health funders are taking to make the health care system more responsive to women.

The Commonwealth Fund

Women's health has long been a priority area for The Commonwealth Fund, and its work in this area has been aimed at increasing public visibility of women's health issues through education, research, and public policy. In 1993, The Fund established the Commission on Women's Health to examine critical issues in women's health and recommend changes in public policy, professional training, and

women's self-care to enhance the health and well-being of women. Over a five-year period ending in late 1998, the Commission focused on access to appropriate health care, prevention and self-care; women's mental health; violence against women and girls; the health of adolescent girls; and the needs of underserved women, particularly low-income and minority women.

The program was launched with a broad agenda, focusing on areas of women's health that had been neglected by research. The Commission's work was guided by findings of *The Commonwealth Fund 1993 Survey of Women's Health*, described earlier in this Issue Brief. Those findings, described earlier, provide insights into the progress made in women's health over the life of the Fund's Commission and the problems that continue to need attention.

In the area of preventive health, the Fund has undertaken a number of projects. The Commission on Women's Health issued *Prevention and Women's Health: A Shared Responsibility* in September 1996 to review the major health risks faced by women, prevention opportunities to reduce those risks, and barriers that impede women from taking advantage of those opportunities. Policy recommendations included in the report called for:

- coverage of preventive services proven to be effective by health insurance plans;
- expansion of education and outreach on health risks and preventive measures;
- improved training of health professionals about prevention and counseling on healthy behaviors; and
- an expanded research agenda focusing on women's health.

Other major projects funded by The Commonwealth Fund include:

- A series of papers and briefings by the Jacobs Institute on Women's Health (co-funded

with the Henry J. Kaiser Family Foundation) on issues in women's health raised by the growth of managed care. Analyses of trends, best practices, policy issues, and research findings were intended to inform federal policymakers, the managed-care industry, providers, women's and other consumer organizations, and researchers.

- A program with the Primary Care Association of Connecticut, in cooperation with 10 community health centers and researchers at the University of Connecticut, to develop and implement a program of screening for domestic violence. Under this program, all community health center staff – from the security guards to the receptionists to the obstetricians – receive training on aspects of domestic violence, so that they can help women and be a resource for them. The Office of Women's Health at HRSA has expressed interest in using this model.
- A grant to the American Association of Health Plans (AAHP) Foundation to identify best practices for serving women in managed-care plans. AAHP has produced a series of reports on women's health issues, including counseling at mid-life, perinatal care, breast cancer treatment, and domestic violence. The aim is to use these reports to develop models for the managed-care industry so that health plans can fully participate in improving women's health.
- Original research exploring how a physician's gender and age may affect rates of breast and cervical cancer screening for patients.

The James Irvine Foundation

In 1994, the James Irvine Foundation launched a \$6.35 million, five-year Women's Health Initiative (WHI). Initially developed to ensure that the health needs of California women, particularly women of color and those with low incomes, would be met under health system reform, the grants program is meant to improve

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Rather than funding grantees solely on an individual basis the James Irvine Foundation brought them together into a group called the Women's Health Collaborative

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the availability and accessibility of culture- and gender-appropriate health information and health services for women, to addressing change at both the policy level and the practice level.

The WHI grew out of two primary concerns: 1) gender differences in accessing and utilizing health care, and 2) pressures and policy reforms that transformed the structure, organization, and financing of health care in California.

The WHI established three primary goals:

1. Increase awareness and understanding of women's health issues – particularly those issues relating to women of color and low-income women – among policymakers, health plans, providers, and the public.
2. Encourage the adoption of public policies to improve the efficiency and coordination of health care delivery systems and introduction of standards of care appropriate to the needs of women by the state legislature, the state Department of Health Services, and/or local governments.
3. Develop and test effective program models for low-income women and women of color to:
 - promote the adoption of healthier behaviors;
 - strengthen understanding of the health care system to enable women to participate as more effective and informed consumers; and
 - increase the utilization of clinical preventive services, with an emphasis on reproductive health services.

The Foundation funded 11 organizations over the course of the initiative to promote the WHI's goals. The grantees were organized under a single umbrella – the Women's Health Collaborative (WHC) – to work together toward their common goals. Within this structure, the grantees interacted by sharing expertise and resources, communicating across cultural

and disciplinary boundaries, and collaborating on specific projects to improve standards of practice or change policy in the health field.

The Office of the Women's Health Collaborative (WHCO) provided overall program coordination for the WHC, and created a forum for in-depth discussions of women's health issues, disseminating information on women's health and identifying potential funds for members' projects. The WHCO identified and linked women's health advocates in California through regular meetings, newsletters, and special committees. The Office also established an advisory committee, which became an additional source of resources and contacts for grantees, and, in some respects, performed a mentoring role. An evaluation of the WHI was conducted by the Institute for Health Policy Studies at the University of California at San Francisco.

Grants have been made in three categories: leadership development, public policy, and community grants. Examples include:

- Funding to the California Elected Women's Association for Education and Research for creation of the California Women's Health Project. The Project conducts public policy research and education related to senior women's health, women's mental health, and violence against women.
- Capacity building for advocacy organizations focusing on health issues of concern to women of color. These include the Women's Health Information Network, operated administered by the Asian and Pacific Islander American Health Forum; the California Black Women's Health Project, a spinoff which operated as the state office of the National Black Women's Health Project; and the Latina Health Policy Project, an effort of the Latino Coalition for a Healthy California.

- Creation of the Women's Health Leadership Program, which is housed at the Public Health Institute. The Program annually selects 50 emerging leaders in the field of women's health (with particular emphasis on women of color working in low-income communities) to participate in a year-long so-called learning community that involves personal leadership assessments, intensive skills building, symposia on women's health issues, and individual community projects.

The Bristol-Myers Squibb Foundation

The Bristol-Myers Squibb Foundation established its Women's Health Education Program in 1993 to address gaps in knowledge about the unique health needs of women and the role that gender plays in health. Women's health is an important concern for the company, and represented an ideal opportunity for the Foundation to make a meaningful impact on a major health issue (Claire Payawal).

The purpose of the Women's Health Education Program is to identify and develop novel approaches to educating women about their health and well-being and to help them become more informed decisionmakers and better advocates for their own health care. The program supports projects that test innovative outreach programs, cultivate partnerships among different sectors interested in women's health, or add new information to the existing body of knowledge in women's health. To date, the Foundation has committed more than \$8.5 million to this program through two primary funding mechanisms: the Better Health for Women Program and General Demonstration Program Grants.

Established in 1996, the Better Health for Women Program generates projects that will help enhance women's health through novel,

integrated, interdisciplinary strategies that improve education, prevention, diagnosis, treatment, and access to care for women worldwide. The program will provide institutional funding of up to \$200,000 over two years to address specific issues in women's health.

Each year, the program's advisory committee identifies an important issue in women's health and issues a request for proposals (RFP) to appropriate institutions in the United States and selected countries.

- In 1996, the Foundation committed \$800,000 to support innovative prevention and intervention strategies addressing cardiovascular disease and women in the U.S. and Brazil.
- In 1997, a total of \$1 million was committed to examine prevention of chronic diseases by addressing health issues facing young women in the U.S., Mexico, and Hungary.
- In 1998, the RFP focused on strategies to reduce the incidence, morbidity, and mortality of lung cancer in women. A total of \$1 million was awarded to five institutions in the U.S.
- A new RFP is being developed in 1999 to address the prevention of HIV/AIDS in women through early detection and treatment of other sexually transmitted diseases. Institutions in the U.S., Brazil, and Thailand will be eligible to compete for these grants.

Since 1993, General Demonstration Program Grants have been awarded to support major initiatives in different areas of interest in women's health. Generally, these grants are for demonstration programs that investigate different models that can be replicated elsewhere to educate women about their health, foster creative collaborations, or add new information.

Following are examples of grants awarded under this program:

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The Bristol-Myers Squibb Foundation established its Women's Health Education Program in 1993, after looking closely across its various business units and recognizing its investment in helping serve the different and changing needs of women across their entire life spans

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The Native American Diabetes Project is a diabetes intervention program that capitalizes on the central role Native American women play in their families and communities, particularly with regard to food preparation and diet.

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- The Black Beauticians Health Promotion Program recruits beauticians who work in low-income neighborhoods and trains them to educate their clients about the importance of breast cancer screening and healthy lifestyles by engaging them in casual conversations. The grant recipient, the Cancer Center at the University of California at San Diego, provides the training. The Cancer Center also serves as a resource for referrals to available health services
- Under a grant awarded to the University of Pennsylvania Medical Center, the Women's Health Report Card Project is working to design and test a framework for measuring and reporting progress in women's health. The goal is to identify eight to ten major indicators that will measure different components of health status for women and corresponding resources spent on appropriate services. The report card will be developed on a national and a state-by-state basis.
- The Native American Diabetes Project is a diabetes intervention program that capitalizes

on the central role Native American women play in their families and communities, particularly with regard to food preparation and diet. The intervention focuses on changing behaviors around physical activity and nutrition as well as family and community support. The University of New Mexico is administering this program in cooperation with several tribal communities.

- The Health Promotion for Women with Disabilities Program, located at the Villanova School of Nursing, seeks to improve the health of disabled women by expanding their access to and participation in health promotion activities. The program includes seminars and educational programs to raise awareness and sensitivity of health providers to the health needs of disabled women.

Outreach and Education

The Aetna Foundation decided to focus on women's health after coming to the realization that women make approximately three-quarters of consumer decisions related to health.

GRANTMAKERS SUPPORT PROJECTS IN ENVIRONMENTAL HEALTH

The effects of in utero exposure to endocrine-disrupting chemicals are of growing concern to many in the health field. Breast cancer activists and scientists, the Endometriosis Association, the Learning Disabilities Association, the American Nurses Association, the Oncology Nurses Association, and the American Public Health Association are among those groups looking for ways to reduce the harmful effects of endocrine disrupters and other environmental hazards on women and their children.

(Rachel Pohl)

Among the grantmakers also taking up this cause are the following:

- With support from the Jessie B. Cox Trust, the Silent Spring Institute is working to identify environmental factors in clusters of breast cancer cases in Cape Cod *(Rachel Pohl)*.
- The Houston Endowment has funded research at the University of Texas Center for Toxicology in Galveston to investigate the impact of agricultural waste on birth outcomes *(Michelle Sabino)*.
- The New York Community Trust funded a study now underway in the Washington Heights section of New York City, a high-density area with a large proportion of low-income residents, to explore the effects of airborne and other toxins on women and their newborn babies *(Jacqueline Elias)*.
- The Paso del Norte Health Foundation in El Paso, Texas, provided support for water and wastewater hookups on both sides of the U.S.-Mexico border and into New Mexico *(Ann Pauli)*.

Women are caregivers of young and old people alike, and can significantly influence their health-related behaviors. They are, then, an important business constituency for the company (Sharon Dalton). Accordingly, the Foundation launched an educational program to reduce the impact of cardiovascular disease, the number one killer of women, through prevention and early detection. Working with Aetna U.S. Healthcare, the Foundation has committed \$7 million to help fund the American Heart Association's National Women's Heart Disease and Stroke Campaign. The Take Wellness to Heart Campaign is a three-year initiative designed to educate women and their physicians and to encourage women to take a more active role in promoting their own health. The campaign includes a national effort to heighten public understanding about the prevalence and seriousness of cardiovascular disease among women. Specific program elements and messages will be targeted to the African American and Hispanic communities.

Improving information for women with breast cancer motivated the Jewish Healthcare Foundation to support the University of Pittsburgh Cancer Institute, the local affiliate of Race for the Cure, and the National Council of Jewish Women in developing an easily accessible, user-friendly patient information system on breast cancer. One component of this project was an Internet-based information service about breast cancer diagnosis, treatment, prevention and early intervention, support, and insurance coverage. Race for the Cure agreed to market the site to community groups (including houses of worship, beauty shops, and grassroots women's organizations), the medical community, libraries, and individuals. In cooperation with its local public television station, the Foundation has also sponsored an hour-long program, The Breast Test, to explain the methods used to screen for breast cancer, the importance of early detection, and possible treatments and their results.

The Susan G. Komen Breast Cancer Foundation funds population-specific outreach projects that address the special needs of a diverse range of women at risk for breast cancer. Each award of \$50,000 is selected through a peer review process recognized by the National Cancer Institute. In 1998, grants for the following projects were awarded:

- linking at-risk populations to breast cancer and mammography information via computer;
- increasing breast cancer awareness and prevention among Native American women;
- disseminating an instructional videotape on breast self-examination technique for women with upper-body disabilities and their health care providers; and
- testing alternative outreach models to reach low-income and minority women with information on breast cancer screening.

In 1999, the Foundation is focusing on improving detection and treatment of cancer in African American women. Programs funded under the African American Women's Initiative include:

- the Witness Project, which encourages African American breast cancer survivors to speak with women at their local churches;
- The East-West Breast Express, which sends volunteers to visit bus stops and train stations in vans equipped to provide free screening and educational information; and
- the Harlem Hospital Patient Navigator program, which enlists outreach workers to canvass beauty salons, senior centers, and other community hubs and steer patients with breast cancer to specially trained navigators who can arrange for emergency Medicaid coverage and provide follow-up visits.

The San Francisco Foundation has supported the "In Our Hands" initiative of the Breast Cancer Oral History Project, which gives low-income women the skills to research, educate,

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The San Francisco Foundation has supported a unique effort to provide clinical breast exams, mammograms, and instruction in breast self-examination to disabled women living in the Bay Area.

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and train others about breast cancer and environmental concerns. Organizations and residents of underserved communities participated in train-the-trainer workshops on topics such as participatory approaches to learning and teaching about breast cancer, oral history as an action research tool, and using the sharing of experiences about breast cancer as a tool to build literacy and leadership skills. Over time, the stories of breast cancer survivors have been captured in a mural that now serves as a teaching tool for women of diverse cultures, literacy levels, and languages.

Several foundations have discovered that faith-based organizations can play an important role in outreach and education. For example, the Bristol-Myers Squibb Foundation is working with The Johns Hopkins School of Public Health in Baltimore on a church-based intervention program around cardiovascular disease. In this project, the church becomes the focal point for recruiting people into the service (Claire Payawal). The Duke Endowment has funded about 20 parish nurse programs, in which nurses employed at not-for-profit, community hospitals essentially are put on the staff of local congregations. Each congregation develops its own health and wellness curriculum. The nurses provide screening services for cardiovascular disease, osteoporosis, and other conditions. When they identify a problem, they refer the patient to the hospital for follow-up services. These programs have been particularly effective in reaching elderly patients (Philip Belcher).

Direct Delivery of Clinical Preventive Services

Many grantmakers are supporting efforts to provide screening services for conditions such as breast and cervical cancer, diabetes, and hypertension. For example, the Blue Cross and Blue Shield of Michigan Foundation has developed a

program to improve the health of African Americans in the state. As part of this program, the Foundation has supported work to assess the frequency and timing of diabetes screening for pregnant African American women and the relationship among maternal glucose level, weight gain during pregnancy, and infant birth weight. The Foundation has also funded an effort to evaluate HIV/AIDS intervention programs designed to reduce risk behaviors for drug-dependent African American women at high risk for acquiring HIV.

Others have funded more modest efforts. For example, the Arlington Health Foundation provided a \$10,000 grant to the local chapter of the American Cancer Society to increase breast and cervical cancer screening. The Columbus Foundation provided \$13,000 to support a blood pressure screening and heart health education program targeting African American women ages 18 to 80. This project is a collaborative effort of the American Heart Association, the American Cancer Society, the Ohio State University Heart Partners, and area beauty salons.

The San Francisco Foundation has supported a unique effort to provide clinical breast exams, mammograms, and instruction in breast self-examination to disabled women living in the Bay Area. The program also offers education and outreach activities to women, their families, and health care professionals about the importance of screening for women with disabilities. In addition, the program has critiqued mainstream educational materials related to breast cancer screening for their sensitivity to the needs of disabled women.

Research

Some foundations are funding both biomedical and health services research on issues affecting women. The opportunities for research, however, may be much broader than currently con-

templated. As pointed out during the Issue Dialogue, when funding research, grantmakers need to think beyond traditional “women’s issues” – like prenatal care, Pap smears, mammograms, and other gender-specific preventive services. They need to see the broader picture that comprises women’s health by using a “gender lens” when thinking about research issues. This lens should be applied to two sets of issues: access and quality. The following illustrates some of the questions that foundation-supported research is, or could be, addressing (Carol Weisman).

Access

Understanding access means understanding not only how women access health services in a changing health care system but also how the changing health care system affects women specifically. A number of questions arise:

1. **How do uninsured women access basic health care?** Data from *The Commonwealth Fund 1998 Survey of Women’s Health* show that rates of uninsurance among women are increasing. These women face specific access issues that may not be apparent without a gender-specific lens.
2. **How are local health care safety nets for women faring?** Although research is underway on safety net systems, rarely does it examine this issue through a gender lens. For example, family planning centers and community-based women’s health centers frequently are not included in this type of research. As more women become uninsured or underinsured and as competition among Medicaid managed-care plans escalates, the viability of health care safety nets for women will become increasingly strained. A 1994 national survey of women’s health centers by the University of Michigan identified strategies that women’s health centers are using to survive in the changing health care system, but more needs to be learned about which strate-

gies work. This is an area of local research that can focus on specific communities and so may be of interest to local foundations.

3. **How do women identify women-friendly providers in their communities?** What information do women need to make informed provider selections and what strategies work best in getting useful information out to women in a timely way?

Quality

Once women gain access to health care services, it is important to determine whether the services they receive are appropriate, of good quality, and effective. A number of questions arise under the issue of quality, including the following:

1. **What is quality of care for women?** Few of the tools developed for measuring quality of care are gender-specific. They are generic instruments that have been developed for use in general populations and they may not be sensitive to the specific needs or concerns of women. There is a need for gender-appropriate measures of services received, satisfaction with care, gender-specific clinical outcomes, functional status, and quality of life.
2. **How does women’s health care vary across sites and among different types of health plans?** Research is needed that compares, for example, women’s health centers with traditional sites for providing health care to women. As quality assessment tools that are sensitive to women’s health issues emerge, funders can build research portfolios on variations across different kinds of organizations that provide information about what works in women’s health care.
3. **What is consumer satisfaction in women’s health care?** Do women perceive quality of care differently than men? Do they perceive quality differently than their providers perceive it? If so, how? A report commissioned

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As more women become uninsured or underinsured and as competition among Medicaid managed-care plans escalates, the viability of health care safety nets for women will become increasingly strained.

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by the New York Community Trust found, for example, that quality is a very subjective term to women (Jacqueline Elias).

Grantmakers currently support a range of research projects. As part of its work in women's health, the Jewish Healthcare Foundation funds research that promotes better prevention and treatment and that encourages application of findings to practice. The Foundation has funded two major breast cancer studies by the Pittsburgh Health Research Institute. The first sought to discover whether women with Stage 1 breast cancer were getting adequate information on the relative merits of lumpectomy versus mastectomy. That study found that although Pittsburgh-area women were relatively well-informed compared with women elsewhere, women who opted for lumpectomies were not receiving the recommended follow-up radiation treatments. The follow-up study determined that physicians were not sufficiently stressing the need for radiation following lumpectomy.

Other grantmakers supporting research include:

- the Healthcare Foundation of New Jersey (support for the Garden State Cancer Center to research the efficacy of radio-nuclide imaging techniques in the early detection of breast cancer);
- the Aetna Foundation (a grant to Emory University and U.S. Quality Algorithms to test what types of physician feedback strategies work best to promote breast cancer screening, first trimester prenatal care, and cervical cancer screening); and
- the Bristol-Myers Squibb Foundation (support for researchers at the University of Washington investigating the effect of estrogen deficiency on body fat and cholesterol metabolism before, during, and after menopause; and evaluating the efficacy of early estrogen replacement therapy in some at-risk women).

Public Policy

Both The Commonwealth Fund and the James Irvine Foundation have a strong policy focus in their grantmaking around women's health issues. The James Irvine Foundation, for example, funded the Jacobs Institute of Women's Health and the Pacific Institute for Women's Health to mount a leadership seminar series in California on the implications of managed care for the health of women. Seminars brought together providers, researchers, community leaders, and women's health advocates to improve awareness and communications about the future of health care services for women and the impact of delivery system changes.

Other grantmakers focusing on public policy include the Ms. Foundation for Women, which seeks to strengthen community-based organizations dedicated to serving women with HIV/AIDS. To this end, the Foundation has supported community agencies working in the areas of prevention, advocacy, and public policy on HIV/AIDS. It has also put violence against women into the public policy limelight by calling for more aggressive prosecution of domestic violence cases and for increased state assistance to victims of domestic violence.

The Henry J. Kaiser Family Foundation focuses much of its work on informing policymakers and other opinion leaders on reproductive health and other women's health policy issues. One of its many national surveys focused on women's attitudes toward mammogram screening. The survey found that more than half (54 percent) of women think mammogram screenings should begin before the age of 40, despite recommendations by health experts to the contrary. Even among the 75 percent of women surveyed who knew that the most recent recommendations by the National Cancer Institute advised mammograms every one or two years after age 40, 60 percent favor regular screenings beginning earlier.

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Do women perceive quality of care differently than men?

Do they perceive quality differently than their providers perceive it?

LESSONS IN COLLABORATION: ONE FOUNDATION'S EXPERIENCE

For grant recipients in the James Irvine Foundation's five-year Women's Health Initiative, collaboration was a requirement. Rather than funding the 10 recipients solely on an individual basis, the Initiative brought them together in a group called the Women's Health Collaborative, which met twice a year during the program's five years.

This collaborative approach had three goals: to promote the leadership, visibility, and credibility of the grantees. The broad strategies embraced by the Initiative to achieve these goals included expanding the grantees' sphere of influence, developing their leadership skills, and building their organizational capacity.

Expanding the Sphere of Influence. Bringing the grantees together in a collaborative structure increased their visibility and credibility as experts in women's health, both locally and statewide. Two things helped make this happen: networking and data.

Among the people invited to attend the Collaborative's regular meetings were the director of the California Office of Women's Health, the regional representative of the federal Office of Women's Health, and a medical director from Kaiser Permanente. Eventually, the grantees became part of a large network, including some prominent policymakers and decisionmakers, thus enhancing their own influence.

The grantees' credibility was heightened by the fact that their policy recommendations were grounded in solid, reliable data on access and use. Some grantees developed their own research capacities; others developed alliances with research institutes that became very important.

Developing Leadership Skills. The Foundation wanted to be able to inform public policy debates with perspectives from the grassroots and from diverse constituencies. Instead of funding a leadership institute, the Foundation developed the Collaborative as a setting where grantees could build their own leadership capacities. The focus was on developing new relationships, trust, and new skills and capacities. In addition, networking with influential people helped enhance the grantees' confidence in their abilities to effect change. The grantees also learned from each other by exchanging ideas and perspectives in an environment where they felt safe and comfortable. Over time, the Collaborative evolved into a strong community of women.

In addition, the Office of the Collaborative engaged in a number of activities that advanced and disseminated the grantees' work. For example, the Office became a clearinghouse of information on women's health and a resource for other organizations. This gave the grantees more visibility and new opportunities to exercise leadership.

Building Organizational Capacity. Grantees learned to be better researchers and consumers of research. In addition, they learned about advocacy and communication and how to disseminate data in effective formats. Finally, with support from the Foundation's evaluation team, which worked as consultants with the grantees, they learned program evaluation skills and how to assess their progress in achieving specific goals.

The Foundation learned several lessons from its collaborative approach:

- Collaboration takes time. Five years was not enough, despite all the resources that were put into the effort.
- Collaborative relationships begin with individuals from different institutions, but institutional relationships and partnerships develop much more slowly.
- Turnover is endemic in the not-for-profit sector. Of the 10 grantee organizations, half experienced a change in executive director. This can cause disruption and delay in building trust.
- Strategic planning at the very beginning of the initiative is important to its success. Programs need to have a mission, core principles, and objectives in place so that they can develop needed structures, benchmarks, and frameworks for evaluation.
- Successful collaboration needs core support for organizational development to develop leadership and other skills.
- Implementation means looking beyond policy research and white papers. It means finding ways to disseminate research results effectively to key audiences. This is both a science and an art, and it requires experience, resources, skill, and timeliness.

MARTHA CAMPBELL

Twenty-One Lessons for Grantmakers

Although only a relatively small number of funders focus on women's health, grantmakers and experts who have addressed these challenges have learned some valuable lessons. Following are 21 insights that several grantmakers have gleaned from their work in women's health. The Commonwealth Fund, for example, learned the following nine lessons from its experience in women's health (Joan Leiman).

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Apply a woman-specific lens to all grantmaking activities not just those focused on women's health.

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1. Think strategically. Use programmatic survey and statistical data to define issues, set objectives, and support a variety of linked activities that are designed to achieve those objectives.
2. Stay focused on the fundamentals, the ABCDs of grantmaking that form the core agenda for women's health and prevention. Those are:
 - Access to health insurance coverage and appropriate, quality care for all women;
 - healthy Behaviors, including weight control, exercise, sufficient calcium intake, smoking avoidance and cessation, and protected sex for adolescents;
 - Clinical preventive services, including mammograms, clinical breast exams, cholesterol measurements, Pap smears, and screening for colon cancer and osteoporosis;
 - detection, diagnosis, prevention, and treatment of Depression and Domestic violence; addressing the needs of Disabled women.
3. Continue to address the disproportionate burden of illness, disability, and access difficulties borne by low-income women. As a corollary to that lesson, look at Medicare and Medicaid as women's health issues.
4. Address the health profiles and needs of women of diverse racial and cultural backgrounds from different regions of the country

and at different age levels. Focus not only on their service needs but their information needs.

5. Consider the problems and impact of informal caregiving responsibilities shouldered by women.
6. Remember to include adolescent girls in efforts to improve women's health. Help parents reinforce healthy behavior in their children.
7. Try to balance portfolios between research and action. In the course of implementing an activist agenda, don't forget the need to learn more about the emotional behaviors and environmental forces that affect women's health. By supporting this type of work, grantmakers can raise the visibility of women's health care needs among policy makers and funders of research. Keep in mind, too, the importance of gathering survey, statistical, and program data on a regular basis.
8. Broker more partnerships and collaborations between public and private organizations, including managed-care plans, in areas where major social investments are needed, such as data collection and public education.
9. Apply a woman-specific lens to all grantmaking activities, not just those focused on women's health.

Others would add to this list:

10. Be creative in grantmaking and look for creativity in grant applicants (Sylvia Drew Ivie).
11. Go farther to determine why women aren't using certain preventive services (Martha Campbell).
12. Create links between screening and follow-up services (Wanda Jones).
13. Work with academic health centers to mine federal data that can help set grantmaking directions (Wanda Jones).

14. Enlist grantees' participation in setting agendas for program meetings. They'll get more out of those meetings (Margaret Hempel).
15. Fund research at the community level (Sylvia Drew Ivie).
16. Along with policy research and advocacy, remember to support service and direct intervention work (Margaret Hempel). Support programs that bring services to women and use other innovative approaches to service delivery (Wanda Jones).
17. When funding community programs, look for anchor groups that can help bring people together. For example, the Ford Foundation's Sistersong program is a coalition of 16 health organizations that target health concerns for women in specific minority communities; the four anchor groups are African Americans, Native Americans, Hispanic Americans, and Asian Americans.
18. Smaller, less structured programs can work at the community level if the issue is hot and there is a hunger for information. That was the experience of the Helen Bader Foundation in Milwaukee several years ago when it sponsored a dementia care network. When the network's one-person office extended a community-wide invitation to anyone with an interest in dementia care to attend its meetings, initial response was strong – and quickly grew even stronger. The foundation's investment was small, but the model took off like wildfire (Robin Mayrl).
19. Help community clinics and other safety net providers for women survive (Sylvia Drew Ivie).
20. Consider the role that faith-based organizations and churches can play in reaching women and their families (Claire Payawal).
21. Look closely at how program products are actually used. The Asian and Pacific

Islander American Health Forum surveyed recipients of one of its policy reports, only to find that most people weren't reading the report because they found it too dense. This revelation prompted the group to revamp its format and come out with a whole new set of products to communicate its research findings (Martha Campbell).

Opportunities For Grantmakers

Foundations and corporate giving programs can play an important role in making the health care system more responsive to prevention and women's health. This issue is important; it is amenable to treatment by grantmaker programs; models are available to guide the work; and there is a natural audience for the results (women and their health care providers). As the examples cited in this Issue Brief show, private philanthropy can make a difference. Other opportunities include:

- developing public information campaigns about what women can do to avoid preventable diseases and conditions;
- conducting surveys to highlight what women and providers know about prevention and where increased efforts are needed;
- funding direct delivery of preventive services;
- facilitating integration of preventive services with other primary care services at community-based sites;
- supporting development of provider and patient incentives to access services;
- funding curriculum development and creation of new training opportunities to make health professionals more aware of the importance of prevention for women through the age span;
- recruiting women, particularly women of color, into the health professions;

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Consider the role that faith-based organizations and churches can play in reaching women and their families

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THINKING CREATIVELY: A COMMUNITY PROVIDER'S PERSPECTIVE ON WOMEN'S HEALTH

To Help Everyone is what T.H.E. Clinic, a 25-year-old, not-for-profit community provider in Los Angeles, is all about. Serving low-income women and their families, T.H.E. Clinic sees about 10,000 patients a year, 75 percent of whom are uninsured and the vast majority of whom are minorities, including African Americans, Latin Americans, and Asian and Pacific Islanders. T.H.E. Clinic's mission is to transform lives and to transform communities through health care and health education.

Prevention is a big part of what T.H.E. Clinic does. And while the concept of preventive health care is universally embraced, there are many in the field who believe that poor people are too ignorant, too oppressed, and too lacking in resources to do what they should for their preventive health care. That belief is probably the greatest obstacle to getting preventive health services to those who are most vulnerable. T.H.E. Clinic's experience shows that it can be done – and done well. The key is creativity. Following are some examples from T.H.E. Clinic of creativity in preventive health:

- *A picture is worth a thousand words. To make a statement against the scourge of HIV and AIDS, a team at the clinic developed a brilliant, vibrant mural called "Healing the Body, Raising the Spirit." In the picture, young people dance, skate, and pray as doves of peace fly into blue skies and death is driven away.*
- *Make prevention fun. "Prevention" as a term can conjure up feelings of duty and drudgery. It doesn't have to. Breast self-exam classes for seniors at T.H.E. Clinic are social events, with tea and cookies and the affirmation that maintaining healthy breasts and sexuality is important to women of all ages. The diabetes management team at T.H.E. Clinic goes by a catchy moniker, the Glucoasters, to engage patients and make them smile. To appeal to young people, a hip hop dancer named Versatile leads a group of 30 middle school students in dance classes three afternoons a week.*
- *Have a conversation. A pamphlet on cancer screening may be easily lost or discarded. But a conversation –repeated over and over by many voices, including those of doctors, nurses, health educators, financial screeners, and appointment clerks – stays in people's minds.*
- *Think outside the box. To reach uninsured Japanese women for breast cancer screening, T.H.E. Clinic takes an old exam table to a department store where they shop. On a Saturday afternoon, a nurse practitioner can see 35 women – hopefully breaking the ice so that they'll visit T.H.E. Clinic for follow-up visits. If Thai garment workers can't take off from work for HIV tests, a team from T.H.E. Clinic visits them at their work place during lunch hour, winning the boss's cooperation by promising to accept any patient who is ill for treatment.*
- *Look for partners in unusual places. Want to encourage Latinas get more Pap smears? Ask a former nun to do a radio spot. It worked for T.H.E. Clinic. When T.H.E. Clinic tried to address youth violence and gangs, it recruited a group of artists to reach young people through art and drama.*
- *Be counterintuitive. For example, to engage a middle-aged woman, support programs that help her middle-aged man. She'll come in with him, and after he's taken care of, she will see to herself. To prevent violence against women, support preventive health for boys, so they can learn to manage anger and their relationships with girls.*
- *Look at the whole woman. To help women with depression, support programs that help them unravel their use of food as a major source of support in their survival. Weight is a retreat from engagement in life.*

Poor people who look to community providers like T.H.E. Clinic for care tend to be at greater risk for most illnesses and health-related problems than other people. However, that's not the message they respond to. They respond to friendship, to genuine expressions of concern about their health and well-being, and to opportunities to work as partners in solving their problems. T.H.E. Clinic's experience shows that foundations can foster these types of relationships by supporting community-based providers that are reaching out to patients in new and creative ways.

SYLVIA DREW IME

- partnering with managed-care plans and community clinics to implement best practice models of prevention for their women enrollees;
- identifying and funding mechanisms targeting women and health professionals that can increase compliance with healthy lifestyle recommendations and other approaches to prevention;
- developing standards and guidelines for women and specific subpopulations, and funding dissemination of these to providers and patients;
- supporting research to develop improved approaches to prevention for women and better treatments for diseases that affect women;
- training and utilizing community health workers to be advocates and health educators on preventive health matters;
- recognizing individuals and organizations in a community that have made important contributions to prevention and women's health;
- working with policymakers and health plans to provide coverage for services proven to be effective in preventing disease and disability;
- encouraging policymakers to focus more attention and direct public resources toward health issues of special interest to women; and
- convening local health officials, providers, and consumers to focus attention on assessment, monitoring, and actions to address prevention and women's health.

Sources

Remarks of presenters and participants at the Issue Dialogue appear throughout this report:

Jeanne Argoff, *Disability Funders Network*
 Philip Belcher, *The Duke Endowment*
 Martha Campbell, *The James Irvine Foundation*
 Sharon Dalton, *Aetna Foundation*
 Jacqueline Elias, *The New York Community Trust*
 Margaret Hempel, *Ms. Foundation for Women*
 Sylvia Drew Ivie, *T.H.E. Clinic*
 Wanda Jones, *US Department of Health and Human Services*
 Joan Leiman, *The Commonwealth Fund Commission on Women's Health*
 Robin Mayrl, *Helen Bader Foundation*
 Ann Pauli, *Paso del Norte Foundation*
 Claire Payawal, *Bristol-Myers Squibb Foundation, Inc.*
 Rachel Pohl, *Jessie B. Cox Charitable Trust*
 Michelle Sabino, *Houston Endowment, Inc.*
 Carol Weisman, *University of Michigan*

Published sources include:

Commonwealth Fund Commission on Women's Health, *Prevention and Women's Health: A Shared Responsibility* (New York: September 1996).

Health and Medicine Policy Research Group, *Improving the Health of Urban Women: Public and Private Funding for Women's Health* (Chicago: May 1997).

Heiser, Nancy, and St. Peter, Robert, *Improving the Delivery of Clinical Preventive Services to Women in Managed-Care Organizations: A Case Study Analysis* (New York: The Commonwealth Fund, January 1997).

Improving Women's Health, HHS Fact Sheet (Washington, DC: U.S. Department of Health and Human Services, March 12, 1999).

Kaiser, Elizabeth, "Women's Health: On a Front Burner," *State Health Notes*, August 3, 1998.

Mead, Molly, *Worlds Apart: Missed Opportunities to Help Women and Girls* (Boston, MA: Women in Philanthropy and the Boston Women's Fund, 1994).

Moore, KG, "A Survey of State Medicaid Policies for Coverage of Screening Mammography and Pap Smear Services," *Women's Health Issues* 2(1):40-49, Spring 1992.

Muchnick-Baku, Sonia, *Corporate Strategies for Women's Health: Survey Results and Case Studies* (Washington, DC: Washington Business Group on Health, 1997).

Perez, Kelly, "Focus on Cancer Screening and Treatment," *State Health Notes*, December 7, 1998.

Shaffer, RB and Corish, C., "Cardiac Surgery and Women," *Journal of Cardiovascular Nursing* 44:14-31, July 12, 1998.

UCLA Center for Health Policy Research, *Fact Sheet: Women's Health-Related Behaviors* (Los Angeles: The Commonwealth Fund Commission on Women's Health, undated).

Weisman, Carol S., "Changing Definitions of Women's Health: Implications for Health Care and Policy," *Maternal and Child Health Journal* 1(3):179-189, 1997.

"Women's Primary Care in Managed Care: Clinical and Provider Issues," *Insights*, Number One (Washington, DC: Jacobs Institute of Women's Health, January 1997).