

Raising Women's Voices for the health care we need

**A collaborative initiative of the Avery Institute for Social Change,
MergerWatch Project of Community Catalyst
And the National Women's Health Network**

A Women's Vision for Quality, Affordable Health Care for All

Why a women's vision?

Women have much at stake in debates over health care reform at the local, state and national levels. The U.S. health care system often fails to meet women's health care needs. It has created tremendous challenges for the women who coordinate health care for our families, who are the majority of health care workers in this country, and who themselves often live with chronic health conditions and disabilities. It is equally important to note that successful health care reform must have the support of women. Research shows that both men and women see women as key health decision-makers for families. Women understand the importance of good quality health care and getting the best value at the best price. They believe in equity, fairness and the basic principle that everyone should be afforded access to the health care they need. In order to be successful, any effort at reform must address the health care concerns that women have for themselves and their families.

Who are the women who have shaped this vision?

Raising Women's Voices has been working with community partners to hold small-group discussions with women from across the lifespan and from a range of racial, ethnic, economic and disability backgrounds and diverse sexual identities. We have asked these women to talk about their experiences with health care and, based on those experiences, what changes they would like to see. We have spoken with teens learning about their bodies and sexuality; young women navigating the transition from education into the workforce; new mothers, reflecting on modern maternity care; recent immigrants to the US; women who are victims of domestic violence; women who have experienced divorce or widowhood; middle-aged women struggling to coordinate care for older relatives; older women coping with chronic illnesses; and women of all ages who are living with disabilities. In addition to these groups, we have consulted with colleagues and members of the RWV Advisory Board, who work on these issues in many diverse communities around the country. These principles are informed by the thoughtful responses of community members and expert advocates alike.

What kind of health reform do women want?

In these conversations, girls and women have consistently identified several key concerns: making quality health care affordable for individuals and families; making sure that everyone is eligible for health care and that coverage can move with people as jobs, family structures, and personal situations change; prohibiting refusal of health care for pre-existing conditions, such as pregnancy, breast cancer, diabetes, arthritis, or back problems; providing greater choice of types and levels of providers, such as midwives; developing programs to improve cultural competency and address health care disparities; and establishing rules to guarantee that health care institutions and health care professionals will provide requested services.

The five central principles outlined here can guide health care reform to better meet the needs of women, our families and our communities. These principles give life and depth to the assertion that health is a human right. Health care policy that is rooted in these principles will be informed by the practical, "kitchen table" wisdom that women bring to these issues. It will also create a health system that ensures our collective health. Empowered by principles that explicitly define a women's vision of our health care needs, women will be prepared to raise our voices for quality, affordable health care for all.

I. KEY PRINCIPLE: Health care coverage must be affordable and always available for women, our families and our communities.

To fulfill this goal, health reform must:

1. Ensure that high quality health care coverage is available to everyone.
2. Ensure that health coverage is available throughout one's lifespan, and is not interrupted by such life transitions as divorce, death of a spouse, changing jobs, moving from school into the job market or returning home from prison;
3. Ensure that health coverage, including any co-payments or deductibles, is affordable to buy and use. Individuals and families may be expected to contribute to the cost of health care, but such contributions should be consistent with their ability to pay;
4. Prohibit disqualification of any individual from health coverage based on a pre-existing condition, such as (but not limited to) pregnancy, asthma, arthritis, diabetes, congenital condition, injury, cancer or any genetic condition or configuration.

II. KEY PRINCIPLE: Health care systems must provide the acute, preventive, chronic and supportive health care services that women, our families and our communities need.

To fulfill this goal, health reform must:

5. Ensure provision of the full range of reproductive and women's health services. Such services should include, but are not limited to, maternity care, pre- and post-natal care, contraception, abortion, treatment and prevention of sexually transmitted infections, and fertility treatment;
6. Ensure voluntary access to preventive care that has been shown through evidence-based research to improve health, including (but not limited to), vaccinations, childbirth education, smoking cessation programs, fitness programs, vision and hearing exams and aids and pharmaceuticals. Additionally, such access should include age-appropriate screening tests that have been shown to improve clinical outcomes, such as mammograms, pap smears, colon cancer screening and blood pressure and cholesterol screening.
7. Include comprehensive dental care for both children and adults;
8. Include comprehensive mental health services that are not limited to drug therapy or any other singular mode of therapy;
9. Include ancillary therapies such as physical, speech and occupational therapy as well as durable medical equipment and disability-related supplies, as needed;
10. Provide support for family caregivers and offer services such as adult day-care, respite care, attendant care and home care that enable elderly and disabled adults to avoid unnecessary hospitalization and to live fully in the least restrictive environment of their choice;
11. Provide end-of-life and palliative care in the final stages of illness and ensure options for end-of-life treatment and support, including access to hospice care at home or in residential facilities, as preferred;
12. Promote greater availability of key health care services -- such as obstetrics, geriatrics and primary care -- that often require longer periods of interaction with health care clinicians in order to provide quality care. Encourage this increased availability by appropriately valuing these services in reimbursement systems and providing incentives for clinicians to practice in these fields;

13. Include comprehensive sexuality education as a core component of health care services by ensuring access to all the relevant information, support and providers that young people need to make healthy and informed decisions.

III. KEY PRINCIPLE: Health care systems must actively work to achieve equity and eliminate disparities in health care provision. They must provide health care that is culturally competent, respectful of and acceptable to patients from diverse communities.

To fulfill this goal, health reform must:

14. Actively address and work to eliminate racial, ethnic, gender and class disparities in health care access, as well as disparities due to immigration status, disabilities and sexual or gender identity;

15. Ensure provision of services that are respectful of people of any race/ethnicity, class, and sexual or gender identity;

16. Provide treatment that is grounded in appropriate gender-based research and research on such social determinants of health as race, ethnicity, income and place of residence;

17. Ensure that people in jail, prison, and immigration detention are afforded access to prompt and appropriate care;

18. Ensure readily-accessible translation/interpretation services, including sign-language services for people who are deaf, whenever necessary;

19. Ensure that health providers and insurers respect the ethical, moral and religious viewpoints of the patient and the medical decisions the patient makes based on those viewpoints.

IV. KEY PRINCIPLE: The health care system must be user-friendly, easy to navigate and transparent.

To fulfill this goal, health reform must:

20. Provide easy-to-understand information about services and providers in multiple languages and at a basic literacy level. All such materials should be available in alternative formats, including large print and Braille. In addition, health plans should offer toll-free help-lines and other types of assistance for understanding options;

21. Support the use of independent advocates and community health educators to assist patients in navigating the health care system, ensure patients obtain appropriate care and safeguard patient rights;

22. Ensure effective coordination of care among multiple providers in collaboration with patients and their families. Patients' records and histories should be documented and transferred between providers and institutions without compromising confidentiality. People should be offered copies of their complete medical records, including those of their children, in easy-to-use formats;

23. Help women and our families make informed choices about health providers, health plans and treatment options by encouraging the development of performance measurement and public reporting. This should include information and statistics explaining the standards of care, outcomes and error rates experienced by patients at hospitals, clinics and all other health care facilities. In a system that promotes transparency, women should have accessible information about such factors of special interest to women as hospital rates of cesarean sections and any health provider policies that restrict the provision of reproductive health care.

V. KEY PRINCIPLE: We must ensure the highest attainable standard of health for women, our families and our communities.

To fulfill this goal, health reform must:

24. Ensure high quality care, with quality defined as the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and remain consistent with current professional knowledge. Use such methods as comparative effectiveness research and current best evidence to ensure good care. Quality measures must incorporate the concerns of diverse constituencies and support efforts to address what works and what does not work for different groups of patients;

25. Require that health systems and providers assist women and families in making informed decisions about the full range of childbirth providers and options available to them. This can be done by providing childbirth education, offering a variety of safe birthing options and access to midwives and doula services. These providers must be accessible in all geographic regions and informed about special risk factors and services needed by women with disabilities who are pregnant;

26. Promote a holistic public health approach to individual well-being and community health by working to ensure that women and families have access to a full range of vital resources, including, fully accessible fitness centers, parks and recreation facilities, community health centers, healthy foods and nutritional assistance.

This vision reflects the contributions and insights of many women who have worked actively with Raising Women's Voices in the development of this set of principles. We especially would like to thank the RWV advisory board, the National Women's Health Agenda Task Force and the organizations that participated in our small group discussions: NARAL Pro-Choice NY TORCH program for teens, the Mount Vernon Senior Center, Medicare Rights Hotline Staff, National Latina Institute for Reproductive Health, a group of labor support doulas and childbirth educators who were convened by Childbirth Connection, members of National Asian Pacific American Women's Forum Leadership Council, Las LUCES of Make the Road New York, Young Sisters for Justice, Boston Women's Fund, Manavi, New Mothers of Washington Heights and Sakhi.

JOIN US!!!

To endorse these principles as an organization and join the movement for comprehensive health care reform that meets the needs of women, our families and our communities, please send a statement of support and your organizational affiliation to eesha@mergerwatch.org or call us at (212) 870 – 2010.