



Protecting Patients' Rights and Access to Care

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**Raising
Women's
Voices**

for the Health Care We Need

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Before the New York State Partnership for Coverage

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Good afternoon. Thank you for the opportunity to discuss the need for ensuring access to affordable, high-quality health care for every resident of our state. My name is Lois Uttley, and I am Director of the MergerWatch project, which is based in New York City. My comments today will focus on the health care needs of women and those family members (such as children and elderly parents) for whom women often arrange care. I will share with you some of the personal stories of New York women and their ideas for improving our health system.

For more than 10 years, the MergerWatch Project has worked with grassroots coalitions across New York State and the nation to protect access to comprehensive women's health care when local nonsectarian hospitals merge with religiously-sponsored hospitals that prohibit the delivery of some reproductive health services. Recognizing that the availability of women's health care is affected not only by the configuration of hospitals and clinics, but also by the system that pays for this care, the MergerWatch project has co-founded a new initiative designed to influence the shape and scope of health care reform. **Raising Women's Voices for the Health Care We Need** is working to articulate women's concerns about our health care needs and those of our families, so that these perspectives can be genuinely considered and fully incorporated into health reform plans.¹ Within New York State, we are coordinating a new **Universal Health Care Task Force of the New York Alliance for Women's Health**.

¹ Raising Women's Voices is a partnership of MergerWatch, the National Women's Health Network and the Avery Institute for Social Change. To learn more, please visit our website at http://mergerwatch.org/health_reform.html

Women have much at stake in the debates over health care reform at the state and national levels in the United States. The current American health care “system” is failing to provide access to needed care for many of these women and for the family members whose health care we often coordinate. The reasons are complex, involving issues of coverage eligibility and limitations, cost, health care disparities, family dynamics and the willingness of health care institutions and individual health professionals to provide requested services. Some of the key indicators of the problem are:

- About 14.1% (1.2 million) of women in New York State are uninsured, according to the latest data from the United Hospital Fund (2007). In general, Latina and African American women are two to three times more likely to be uninsured than are white women (2000 U.S. Census in The Henry J. Kaiser Family Foundation’s *Fact Sheet: Women’s Health Insurance Coverage*, July 2001).
- A higher percentage of women in New York (19.4 percent) are dependent on public insurance programs than are male New Yorkers (14.2 percent) (United Hospital Fund, 2007).
- Some 17 percent of the New York women contacted in this year’s “Unheard Third” survey by the Community Service Society said they didn’t get or postponed medical care. That figure is up dramatically from 11 percent in the last CSS survey four years ago in 2003. The survey also found that New York women have less savings to fall back on if hit with medical bills than they did just four years ago (Community Service Society, 2007).

To develop a policy framework for health reform that meets the needs of women and our families, we have been sponsoring small-group discussions with diverse women’s constituencies within the New York metropolitan area. They included:

- Older working-class women (primarily African-American and Caucasian) at a senior citizens center in Mount Vernon
- Women in Washington Heights who gave birth within the last three years
- Women who were victims of domestic violence
- A diverse group of teenagers (girls and boys) who participate in a peer leadership and advocacy program in Manhattan
- Volunteers on a Medicare help hotline in Yonkers
- Labor and delivery nurses, doulas and childbirth educators working in New York City hospitals
- Asian-American women (both recent immigrants and members of the second generation of immigrant families)

We asked these women about the problems they and their families are having getting health care, and we invited their ideas about how to reform the system. My comments below are based on their experiences.

Problems

Women with health insurance coverage reported declining quality of coverage and increasing costs for premiums, co-pays and deductibles.

- One woman noticed that the coverage available to her from her husband's insurance plan, "has gotten dramatically worse. It is unbelievable how much it has changed in the last eight years." She described being denied coverage for treatment for a yeast infection, including the cost of prescribed medication, because she is only covered now for one office visit and one pap smear per year. After many phone calls, she said, she finally got "most of it covered." She asked: "When did it go from 'I go (to the doctor) when I need to' to 'that is all you get?'"
- A teenager told us, "The doctor gave me a prescription to get filled at a pharmacy. I have insurance that requires me to pay a co-pay but when I went to the pharmacy they said I had to fill out a form and mail it into the insurance company to see if the medication is covered. I didn't have the form so I had to pay full price – it was like \$150. They then told me in order to get medication and not pay full price, I would have to fill out this form two weeks ahead of time."
- Co-pays for prescription drugs can be as much as the drugs themselves, one woman said, citing a \$30 co-pay for a \$35 drug. Another woman said she stopped going to the doctor because of the high co-pay on her plan.
- A South Asian woman reported that "when I go to India, I get my supply of antibiotics and any other medications I may want to have for the year." She and colleagues from the South Asian community agreed that many OTC drugs in India are not only cheaper but better than the ones available here.

Women explained that they play key roles in family medical decision-making and are struggling to arrange, or personally provide, care for elderly parents, children, siblings and other relatives. The consequences for these women can be lost work time and wages, as well as stress-related personal illness.

- Women struggling to care for their loved ones reported they are facing difficulty securing existing services that are not "braided" together into one comprehensive system. Because most insurance does not offer home care coverage, they often find it prohibitively expensive. Those who are able to utilize home care are generally unsatisfied with the service as it is generally considered by society as an undervalued occupation.
- "I was really sick and had to go to the doctor," reported one New York City teenager. "My sister has to be at work at 8am, which was also the first opening for the doctor. My sister couldn't leave me at the doctor's office because I needed to have a guardian there in the office. We waited and waited, other people were taken before us, when I asked them what was taking so long they said the health card was giving them a hard time. So we had to wait and we didn't get in to see the doctor until late – my sister had to lose a day of pay because she couldn't get to work."
- "Last year, my mother was having a lot of health problems and had to go to the hospital," a woman recalled. "Three family members took turns being in the hospital overnight with her because of the lack of care and attention to her. We

kept wondering what about the people who don't have family to fight for them to get pain killers and whatever treatment they need in the hospital."

Those women who do have private health insurance are often at risk of losing it. Examples offered included the loss of dependent coverage through divorce or the gap that can occur between college and a first job.

- One young Asian American woman told us that "there are so many gaps in coverage, especially in the period between college and finding a job." Many such young women forgo coverage during this time, because of the cost and put themselves at risk of severe financial burden if they become ill.

Even when women do have health insurance coverage, they have no guarantee that their local hospitals, clinics, pharmacies and doctors' offices they want to use are included in their plan or will provide the reproductive health care they need. Pharmacist refusals to dispense contraception was one example. A special problem cited was the reluctance of insurance plans to cover midwives and birthing centers.

- K., who works as a labor and delivery nurses at the birthing center of a New York City hospital, said "a lot of women call the birthing center and ask, 'Do you take our insurance?'" The answers often are complicated, she said, explaining that the hospital might be covered by the insurance, but not the individual provider. "It's definitely a lot of legwork," she said. "You have to make a lot of phone calls."
- Determined to switch from hospital maternity care to a birthing center, one young mother-to-be found that her insurance "made it practically impossible for me to transfer my care to the birthing center." To prevail, she said, "I called everyone at the insurance company. I wrote a letter to the CEO of (Plan X). I called Hillary and (State Senator) Erich Schneiderman. In the end, they didn't deny me my care." As a result of her persistence and success, the birthing center began to refer other patients to her for help in navigating the restrictions of their insurance plans

Those without health insurance said they are finding it more difficult to obtain health care at clinics, as well as other social services.

- Women of South Asian descent reported they have encountered racism and prejudice at local hospitals for being uninsured and foreign born.
- Women reported that undocumented immigrants are now getting carded at the pharmacy for OTC drugs like sinus medication and cold medicines. The only alternative to getting those drugs is to wait at the doctor's office for two to four hours, they said.
- Survivors of domestic violence cannot afford dental care to fix problems caused by battery to the face.
- "There is no continuity of care in this system," a South Asian woman told us. Adding, "there are no follow-up phone calls from doctors, and no messages left

are returned with a call to provide an answer. The only way to get additional help is to go back to (the doctor's) office.”

Women interviewed said they are generally not satisfied with the quality of care they receive in the current system, regardless of their insurance status.

- Labor doulas and nurses spoke of the low quality of care given to women during birth and the lack of informed consent for interventions that are rarely medically indicated. They attribute this to a lack of consumer education about childbirth and the medicalization of birth that has been driven by malpractice concerns.
- Some of the immigrant women interviewed criticized this country's tendency to medicalize every ailment, which they believe encourages the over-prescribing of medications.
- Teenagers said they generally don't feel listened to by health professionals and strongly urged that health and sex education be started at an earlier age. They also said they feel that the two of the major health concerns of teenagers – addiction and self-mutilation – are not adequately addressed by the health care system.

Women reported their frustration with trying to understand how the system works.

- “Even though when we arrive, the individuals (practitioners) themselves seem to be kind and somewhat competent, [but] negotiating the institutions themselves is somewhat daunting,” said one woman.
- “My mother-in-law had Medicare and threw up her hands in disgust saying, ‘I don't understand all these bills.’ [And] it is the women who end up with all this health care for their mothers.”
- Maternity nurses and doulas pointed out that individual plans, almost without exception, will not take on a pregnant applicant based on a pre-existing condition.

Solutions

Despite their diverse backgrounds, the New York women we interviewed have similar ideas of change that could improve the current health care system. Some of these ideas are well-known; others are innovative and forward-thinking.

Women want health care to be accessible and affordable for everyone.

Women believe that health care should be universal and non-exclusionary. Undocumented residents and the mentally ill, especially, should not be left behind, these women said, citing the consequences not only for the patients, but for the rest of society with whom these individuals come in contact.

Women want more affordable insurance plan options and help navigating the insurance bureaucracy.

Women who are uninsured want access to more reasonably-priced insurance plans that allow them decent coverage and take into account their income when setting co-pays. Many cited the lack of dental coverage as an especially difficult problem, especially those

women who are victims of domestic violence and have suffered battering of their faces. Insured women want their insurance carriers to provide information that is understandable and easily accessible, when trying to clarify details of the plan or to get certain treatment covered. This information must be easy to read and available in alternative formats for the disabled.

Women want access to comprehensive reproductive health care from the time they are teenagers, and want better options for childbirth.

Teenagers called for early and comprehensive sex education, both through their health providers and in schools. Doulas and young mothers wanted easily available and affordable childbirth education, as well as unbiased information about all available birth options, including midwifery.

Women want a patient-centered health care system.

Women want to spend less time in the waiting room and more time with their health care providers. They want to have access to preventive medicine and more consistent follow-up care. They want the option of home visits by care providers for those patients who are immobile. They want better transparency in the system, especially through access to information about their local hospitals' health outcomes.

Women want to have access to all available information about their health care needs in order to make informed choices regarding their health.

South Asian women said they want information about all available treatment, including culturally compatible alternatives. Seniors cried out for patient advocacy services to help them formulate questions about their medical conditions, decisions, treatments and insurance coverage.

Women want to be treated by culturally competent practitioners.

Women want their individual concerns to be heard when they seek health care, and they want to be assured that their health is attended to with competence and consistency. Some of the South Asian women cited a desperate need for more translators and/or practitioners who speak languages other than English. Women want to see adolescent medicine, preventative care, the midwifery model of care and end-of-life care receive more attention from the health care system in general.

Women believe that medical education needs improvement and that home health care needs to be professionalized.

Because they want to interact with a care provider who is sensitive to their health needs but also their particular backgrounds, women believe training should include a community health placement to expose doctors to a diverse cross-section of the population. Teens recommend that medical schools offer affordable education to help diversify the profession as well. They also said that home health aides deserve to be paid a decent wage and be allowed opportunities for work advancement in order to give the occupation the respect and value it deserves.

Women's concerns about health care are far reaching and reflect their role as caretakers in our society. These voices are valuable and should be given the credence they deserve. We at MergerWatch hope that the New York Partnership for Coverage will respect and incorporate these voices and viewpoints into its work so that New York's health care system responds to the needs of its residents.