The Well-Woman Project

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THE WELL-WOMAN PROJECT:

PROMOTING THE WELL-WOMAN VISIT AND THE WELL-WOMAN

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PROJECT SUMMARY

The passage of the Patient Protection and Affordable Care Act of 2010 (ACA) provided healthcare coverage to millions of uninsured and underinsured Americans, eliminated discriminatory coverage practices such as gender rating and pre-existing condition exclusions, and improved access to preventive care by prohibiting cost sharing requirements for the provision of preventive services and screenings including a preventive services visit for women[1], or the Well-Woman Visit (WWV). Although increasing awareness of, access to, and utilization of the WWV is a key strategy for engaging women of reproductive age in health care and has become a key strategy in an effort to promote the use of preconception/interconception care[2], it is also recognized that medical care is only one piece of the puzzle related to improving women's health and infant health (among women who become pregnant). Emphasis on upstream factors and the Social Determinants of Health (SDOH) has gained increasing attention as structural forces are increasingly understood to be a main driver of health status and health inequities[3-4].

8 Cities:
Boston, MA
Chicago, IL
Detroit, MI
Jackson, MS
Nashville, TN
New Orleans, LA
Oakland, CA
Omaha, NE

Given this context, the W.K. Kellogg-funded Well Woman Project, a collaboration between investigators at the University of Illinois School of Public Health and City-MatCH, aimed to gather women's views and stories with respect to the Well-Woman Visit and the conditions of women's lives that affect their ability to be well-women and seek well-woman care. This was accomplished by gathering women's stories through Listening Sessions in conjunction with 8 urban health departments, and through a 24/7 VOIP Story phone line and a confidential WWP Story blog/website available to women across the 8 cities as well as nationally. During the Spring of 2016, 156 women participated in the Listening Sessions in the 8 participating cities, with an additional 104 Stories collected via the phone line and blog. Data from both sources were transcribed, translated when necessary, and analyzed using Dedoose, a qualitative software program.

Analysis of Listening Sessions and Stories was conducted by examining and documenting patterns ("themes") present within the Listening Session discussion and shared Stories transcripts. The themes which emerged are based on commonality of ideas and opinions expressed by women in each respective city, across all cities, and across the shared Stories; no theme was based on comments from just one or two women. In response to the themes, recommendations were generated through an iterative process and are comprised of ideas that came from: 1) the women who shared their experiences; 2) the research team's partners/stakeholders; and, 3) the research team itself. In the next few pages, important information about the Well-Woman Visit and women's use of preventive services is provided along with the themes and recommendations for change generated by the Well-Woman Project.

Goal: To elevate women's voices about what makes them healthy and able to access and utilize Well-Woman Care within the context of their lives, neighborhoods, and cities.

The Well-Woman Project

WHY A FOCUS ON THE WELL-WOMEN VISIT AS A TRIGGER FOR ACTION ON WOMEN'S HEALTH?

Access to quality preventive care is a key factor that impacts a woman's ability to be healthy across the lifespan. The ACA shepherded a transition from a reactive healthcare system to one that champions prevention. The women's health amendment to the ACA requires new private health plans and Medicaid coverage for newly eligible women to cover preventive healthcare services for women with no cost sharing requirements[5]. In 2011, the Institute of Medicine (IOM)[1], recommended that eight clinical preventive services for women be covered without cost sharing including: screening for gestational diabetes, HPV testing, counseling for STIs, counseling and screening for HIV, contraceptive methods and counseling, breastfeeding support, supplies and counseling, screening and counseling for interpersonal and domestic violence, and an annual preventive visit. On August 1, 2011, the Department of Health and Human Services adopted the IOM recommendations. Incorporating an annual preventive visit to provide many of the services recommended by the IOM is particularly important due to women's disproportionate burden of chronic disease even though women interface with the healthcare system more than men[6]. While women may interact with the health system more than men, data from the Kaiser Family Foundation[7] indicate that prior to the ACA, there were significant inequities with respect to the use of an annual preventive care visit by women, particularly based on insurance status, poverty level, and health status. As such, health professionals and policy-makers have sought to increase awareness about and access to the well-woman visit in order to improve women's health for its own sake, and in the case of reproductive age women who have children, as a strategy for improving adverse pregnancy outcomes. In order to leverage the benefits of the well-woman visit, it is not only necessary to focus on improving women's access to medical care, but to understand the context of women's lives, such as employment, access to healthy homes, nutritious foods, safe neighborhoods, and adequate transportation, and the many competing priorities that affect their ability to be "well" women.

Components of Well-Woman Care

According to the American College of Obstetricians and Gynecologists (ACOG)[8], the WWV is a "fundamental part of medical care and is valuable in promoting prevention practices, recognizing risk factors for disease, identifying medical problems, and establishing the clinician–patient relationship". In 2013, ACOG convened the Well-Woman Task Force to identify age-specific well-woman visit guidelines across the lifespan[5]. In March of 2016, ACOG launched the Women's Preventive Services Initiative (WPSI) to "develop, review, update, and disseminate recommendations for women's preventive health care services". WPSI recommends women receive annual preventive care visits beginning in adolescence and continuing across their lifespan and also emphasizes that the WWV is a much-needed opportunity to provide preconception care[9]. Age-specific recommendations for well-woman care can be found at WomensPreventiveHealth.org.

WHAT DO WE ALREADY KNOW ABOUT WOMEN'S ACCESS TO AND USE OF WELL-WOMAN CARE?

Several health system factors affect women's use of preventive care including access, insurance status, cost, availability, and relationships with providers. One study found that despite the ACA's emphasis on preventive care, "forty percent of women are unaware that they are entitled to WWVs under the ACA and one in five women postpone preventive care owing to cost"[10]. In multiple studies, not having a usual source of care and/or lacking health insurance were found to be strong predictors of the utilization of preventive services[11-14].

Independent of insurance, women report many barriers to care when navigating the healthcare system. There are multiple logistical issues such as inconvenient office hours, competing demands, and lack of child care and transportation[10] [15-16]. In addition, in a study on prenatal care utilization, women described differential treatment based on type of health insurance as well as differential treatment based on race/ethnicity[17]. Further, a patient's race and socioeconomic status can affect a physician's perception of the patient[18-19]. Relationships with providers are important for all women. Women prefer providers who are

nonjudgmental, trusting, and good listeners as well as those who display empathy and encourage patient engagement in their care and the use of services[11] [15].

With respect to non-health system factors, socioeconomic status serves as a significant predictor of preventive care use. Lower socioeconomic status acts as a substantial barrier to women utilizing preventive services[11] [14] [20]. Women with higher education, high income, and who are employed are more likely to use preventive services[12-14] [17] [21]. The social context in which women live their lives also affects their preventive care use. Several studies have found that married women are more likely to utilize preventive services relative to those who are not married[12] [22]. Interestingly, one study found women with high levels of familial social support to be less likely to pursue preventive care. However, as social support from friends grows so does the likelihood they will utilize preventive care, seemingly because the indirect experiences women have with preventive care through their peers increases their probability of use[23].

WHAT WAS LEARNED FROM THE WELL-WOMAN PROJECT?

Themes: Health System Factors That Affect Women's Use of Preventive Services

The Well-Woman Project identified multiple health system barriers which deter women from utilizing preventive services and negatively affect their ability to be healthy.

First and foremost, participating women reported health care cost and insurance barriers. Women face barriers in obtaining any or low-cost insurance and report issues with copayments, deductibles, and premiums; they reported avoiding seeking health care because they are afraid they cannot afford the associated costs or fear going into debt or filing for bankruptcy due to medical bills. They also frequently discussed that the quality of care they receive depends greatly on their insurance type. In general, the vast complexity of the healthcare system prevented many women from seeking care or obtaining care. Several women documented feeling overwhelmed with tasks when joining a new insurance plan such as finding providers within their network and navigating new healthcare facilities and systems, as well as difficulties related to making appointments and adhering to the referral requirements of their insurance policies. Some women expressed that insurance coverage was clearer during pregnancy and as such, some expressed that they did not seek healthcare services until pregnancy for this reason.

Themes* that Emerged from Listening Sessions and the Stories:

1. **The healthcare delivery system is not woman-friendly.**
2. **Women's competing demands and priorities make accessing health care difficult.**
3. **Women weigh costs vs. benefits when deciding to access care.**
4. **Relationships with providers are key to women's decisions about accessing care.**
5. **Health and insurance literacy empower women to advocate for themselves and others.**
6. **Positive mental health is integral to being a "healthy" woman.**
7. **Healthy food, safe environments, and opportunities for physical activity are vital for women.**
8. **Social support systems facilitate women's willingness and ability to seek care.**
9. **Lack of childcare and transportation are major impediments to accessing health care.**
10. **Fear is a pervasive component of many women's healthcare experiences.**

* Themes are based on commonality of ideas and opinions expressed by women in each respective city, across all cities, and across the shared Stories.

Women also referred to interactions with healthcare providers as a significant barrier to utilizing preventive services. Lack of trust or comfort was a major issue; women felt they were not always heard, and that many providers did not address their concerns.

The structure of appointments, specifically not being able to get a timely appointment and not having sufficient time with the provider, often caused women to delay or defer seeking healthcare services. Many women expressed being discriminated against by

their providers due to their race or ethnicity, socioeconomic status, type of insurance, disability, and sexual orientation or gender.

A lack of health and/or insurance knowledge or literacy also serve as barriers for many participants. Some women lacked basic knowledge about their bodies and many did not have previous experience with primary care or understand how to navigate the healthcare system. Given an expressed lack of health knowledge or literacy, women expressed fear about multiple issues. In addition to fear related to finances, several expressed fear about being judged or stigmatized for utilizing care and/or fear about the content or results of the visit. Many reported fear related to lack of citizenship or immigration status, while some feared the loss of confidentiality. Spanish-speaking women often noted the lack of translational services and materials available in Spanish which made it difficult or undesirable for them to seek care.

City-Specific Themes that Emerged from Listening Sessions and the Stories:

1. **Women report differential treatment based on their race or ethnicity. (Boston, Jackson, Chicago, Oakland)**
2. **Women report differences in the quality of and access to care based on their insurance status. (Chicago, New Orleans, Detroit, Oakland, Nashville)**
3. **For many women, pregnancy was their introduction to the healthcare system. (Chicago, Nashville, Detroit, New Orleans, Jackson, Oakland)**
4. **Women report that low-income individuals are treated poorly compared to others. (Nashville, Omaha)**
5. **Women report difficulty or fear in accessing care if they do not have U.S. citizenship or do not speak English. (Boston, New Orleans, Chicago, Oakland, Jackson, Omaha)**
6. **Family and cultural beliefs are barriers to seeking care for many women. (Boston, Jackson, Omaha, Chicago, Nashville, Detroit, Oakland)**

Themes: Non-Health System Factors That Affect Women's Use of Preventive Services and Their Ability to be Well-Women

Along with health system barriers, women indicated that many non-health system factors negatively impacted their ability to seek and utilize preventive services and affected their ability to be well-women.

Many women serve in a multitude of roles, many of them involving caretaking. Women described the "second shift" and the competing demands of their work, family, and home duties which often prevent them from being healthy and seeking care. Women also discussed barriers related to transportation and child care which affected their ability to obtain care. Women in many cities reported long distances to providers, no available parking, and unreliable and unsafe public transportation when traveling with small children including no room for car seats or strollers on buses, in particular. Women also discussed unreliable transportation services which are not women and family-friendly (e.g., van services reimbursed by Medicaid). Several women reported being unable to take their children to their appointments due to a lack of child-friendly clinics and/or being unable to obtain child care in order to attend their healthcare appointments. Women also discussed having jobs that do not offer paid sick time, personal days, or vacation time which results in loss of pay to see a healthcare provider. Some also expressed being unable to make traditional office hour appointments due to their inability to take time off during the day.

Women discussed living at long distances from family members and having inadequate support networks to draw upon to get assistance with family-related tasks which in turn affected their ability to be healthy. Women also described family and cultural barriers, specifically with respect to accessing sexual and mental health services. Perceptions and beliefs held by family and friends affected how frequently women sought care; some women documented using "home remedies" and self-care outside of formal medical settings to avoid seeing a provider.

Although many women expressed a desire to eat healthy and to cook healthy foods, there were many barriers preventing them from doing so. Due to limited access to grocery stores stocked with healthy options and neighborhoods that only seem to support unhealthy food choices, some women documented traveling long distances to buy healthy groceries for themselves and their families. Many women believe that although healthy eating is important, it is expensive and time-consuming. With the competing demands of their lives, women often find it difficult to cook healthy, well-balanced meals for themselves and their families. Likewise, the non-walkability of some neighborhoods can prevent women from engaging in healthy behavior such as exercise or spending time outdoors with their families.

Living and working in high crime neighborhoods and/or unsafe environments often causes women to consider how to survive in their current living situations, rather than how to thrive and improve their health and well-being. Women stated that sometimes they avoid mental health services because they do not believe providers can relate to their lived experiences in high crime areas. Some women moved to safer areas to protect their families, access better housing, as well as better school systems.

WELL-WOMEN PROJECT RECOMMENDATIONS

The recommendations developed by the Well-Women Project are aimed at City Health Departments with a focus on their ability to galvanize other health system and community partners to create policy and systems level changes in their cities.

Goal: Employ strategies that mitigate the complexity of the healthcare delivery system and make navigating care easier.

Recommendations:

- Adopt and promote a Charter which delineates the components of a women and family-friendly health delivery system.
- Engage in dialogue with large health systems and federally-qualified health centers (FQHCs) to encourage increased availability of online appointment scheduling and appointments outside of traditional hours, drop-in/walk-in appointments, more time per patient to facilitate patient-provider interaction, an increase in the availability of on-line/phone healthcare consultation, and the ability of providers to conduct home visits and/or provide care through mobile clinic sites.

Goal: Employ strategies that assist women in prioritizing health care.

Recommendations:

- Depending on city context, create a city-wide task force to include key stakeholders to consider adoption of paid sick leave for both public and private employees.
- Develop policy and educational materials focused on city-specific sick and personal leave policies.
- Develop policies or laws which require employers to allow people one day off per month (for example) without being questioned or requiring documentation.

Goal: Increase transparency and lower healthcare costs.

Recommendations:

- Partner with major health systems, FQHCs, and other key stakeholders to provide women and families with access to insurance navigators on a year-round basis. Initiatives such as a city-wide insurance navigation hotline and on-line insurance navigation support can help women understand insurance and network options.
- Develop a city fund to cover uninsured women and families and/or help women and families struggling with high deductibles for their privately obtained insurance.
- Partner with major health systems and FQHCs to sponsor “One Day” Medicaid/free care several times a year for all.
- Increase the presence of school-based health centers as a way to improve access to contraception and family planning for younger women.
- Provide “cost estimators” for procedures and specialty care that are easily accessible and user-friendly for women and healthcare providers.
- Work with insurance carriers to increase transparency with respect to costs and coverage. For example, insurance carriers might:

- Increase messaging and outreach about the fact that preventive care is covered without cost-sharing for plans purchased through the health insurance marketplace and for newly eligible Medicaid recipients.
- Provide incentives to women and their families for obtaining preventive services.

Goal: Increase trust, comfort, and rapport between women and providers, including providers' staff.

Recommendations:

- Explore approaches to the development of a women-centered, consumer-driven mechanism to enable reviews of providers and enable women to recommend women-friendly provider sites.
- Partner with major health systems and FQHCs to develop and offer training to: increase the cultural competency/humility of the clinical workforce; to facilitate the implementation of "One Key Question for Patient Provider Communication": (e.g., Is there anything I can describe again to make sure you understand what we just discussed?); to increase the number of health navigators and interpreters at clinics/provider's offices; and, to develop electronic communication/telehealth strategies which allow patients to communicate with providers outside of office visits.
- Explore approaches that enable women to have their health herstories available on personal "apps" so that providers can readily access this information.
- Support the provision of training in trauma-informed care for providers.

Goal: Increase access to health education and improve health literacy to empower women to advocate for themselves and others.

Recommendations:

- Partner with health systems and other key stakeholders: to support and develop health education campaigns, including the Show Your Love campaign, that focus on women's understanding of the importance of their own health and health care; to ensure the availability of a city–wide Women's Health Hotline as a go-to-resource for up-to-date information on changing health and health care recommendations and guidelines; to provide interactive education in clinics while women are waiting to be seen by providers (e.g., videos, education kiosks, health educator on-site to answer questions); to develop healthcare materials in plain language; and, to offer women's health discussion groups/support groups in which women can discuss their health concerns and questions about how to navigate the healthcare system.
- Provide resources and trainings for women and families focused on how to advocate for oneself/family with both providers and insurance companies.
- Provide updated lists of available providers, including the types of insurance policies they accept, as well as providers or healthcare facilities that offer free or sliding scale services.
- Offer an "Ask the Doctor Day" in health department, healthcare, or community settings.
- Work with city school systems to increase the emphasis on preventive care during school-based health and sexual education.
- Develop health department sanctioned online chat sites in which healthcare providers, pharmacists, nurses, insurance providers, etc. are available to answer health-related questions in different languages.

Goal: Improve access, affordability, and social acceptability of mental health care.

Recommendations:

- Work with community partners to ensure the availability of community-based resources for self-care and respite (e.g., yoga, mindfulness, stress reduction, exercise, drop-in centers, etc.).
- Support increased access to mental health care through initiatives such as a psychiatric consultation line for primary care providers, and telemedicine options for patients.
- Partner with major health systems and FQHCs to increase care coordination between mental health and primary health care providers, to educate communities about the importance and realities of mental health care to prevent stigma, and to support strategies to diversify the mental health workforce.

Goal: Improve access to quality food and safe and affordable environments for physical activity.

Recommendations:

- Explore "food prescription" approaches and/or community-supported agriculture (CSA) programs through partnerships between local farms, healthcare providers, and health departments to increase access to fresh fruits and vegetables.
- Work with major health systems, FQHCs and other stakeholders, to explore ways to improve women's and families' ability to apply for Supplemental Nutrition Assistance Program (SNAP) at their healthcare providers' offices.
- Work with community partners to support the provision of community-based programs focused on how to use and cook healthy foods (e.g., Cooking Matters).

Goal: Promote personal and system-facilitated social support networks to increase women's willingness and ability to seek care.

Recommendations:

- Explore the development of a cadre of women's health peer advocates (volunteer or paid) who can be present at women's appointments.
- Work with health systems, FQHCs, and other stakeholders to increase "group" approaches for specific types of care (e.g., prenatal, family planning, diabetes, obesity, cardiovascular health, etc.).

Goal: Improve transportation provided through Medicaid/insurance and increase accessibility of public transportation for women and children.

Recommendations:

- Work with large health systems and FQHCs to: encourage their partnerships with ride-sharing organizations to transport patients and their families to and from their medical appointments; encourage the provision of free parking vouchers or free or discounted bus/train cards to attend appointments; and, encourage health provider sites to provide play areas or supervised childcare facilities in their clinics/offices.
- Engage with the City Department of Transportation to explore and develop plans to provide women and child-friendly public transportation (e.g., special seating that allows for the placement of car seats and strollers).

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