2nd Annual NIH Vivian W. Pinn Symposium Putting Science to Work for the Health of Women

## Healthy Women Make Healthy Communities: Women as Makers

## Welcome

Janine Austin Clayton, M.D., NIH Associate Director for Research on Women's Health and Director, ORWH, opened the symposium by underscoring the office's mission: to raise the bar for the health of women. ORWH's efforts build on the trailblazing example of its founding director, Vivian W. Pinn, in whose honor the symposium is named. The women selected to present their research address ways to reverse trends toward shorter lives and poorer health for women and to highlight women's role in healthy families and communities. In highlighting ongoing efforts to raise the bar for women's health, they, too, carry on Dr. Pinn's inspiring example.

## Opening Remarks

Vivian W. Pinn, M.D., Senior Scientist Emerita, Fogarty International Center, and Former Director, ORWH, reflected that a generation has passed since ORWH was established. In the initial years, the office needed to carve a path to something different. Even the need for ORWH's work was not widely understood or accepted. Today, it is no longer necessary to explain what women's health is and why it is important, but there is value in talking about these things so that the younger generation understands how far the field has come. There is much to be proud of in what the office has accomplished and what it continues to do.

## 2017 Director's Award

Davene B. McCarthy White, M.P.H., R.N., NNP, received the inaugural ORWH Director's Award for caregiving in the field of nursing, particularly for her work with the children and families of Washington, D.C. A clinical assistant professor in the Department of Pediatrics and Child Health at Howard University College of Medicine, Mrs. White has a 46 -year career as a neonatal nurse practitioner, clinical researcher, professor, and community activist. She established the Boarder Baby Project in 1989 to provide care and follow-up for drug-exposed and neglected infants and those whose mothers were HIVpositive. She also directs three support groups at Howard University Hospital: the Comprehensive Area Resources, Entitlements, and Services public health program, which provides support services for HIVpositive individuals and their families; the National Breastfeeding Support Center; and the Women, Infants, and Children Family Center.

## Enabled and Empowered: How Healthy Women Create Healthier Societies

 Jacquelyn Caglia, M.P.H., Associate Director, Women and Health Initiative, Department of Global Health and Population, Harvard T. H. Chan School of Public Health, presented the results of a three-year assessment of women's health conducted by the Commission on Women and Health. The commission, which brought together 15 experts from around the world, was a partnership between The Lancet, the Harvard T. H. Chan School of Public Health, and the University of Pennsylvania School of Nursing. The commission published its work in The Lancet in 2015.The commission reframed the concept of women's health to incorporate both women's health and their role as health caregivers. Conventionally, discussions about women's health have focused on maternal and child health and reproductive health. The commission developed a conceptual framework that addresses the roles women play as producers and recipients of health care across the lifespan. The
framework also underscores the importance of including all life stages - conception, infancy, childhood, adolescence, adulthood, and old age - and address conditions like cardiovascular disease that are not specific to women but that affect them differently. Areas that have been overlooked include the increasing burden of self-harm on adolescent girls' health and the rising caregiving demands of dementia and other conditions later in life.

The commission identified different levels at which caregiving - paid and unpaid - falls predominantly to women: in the household, in the community, and at health care institutions. Care provided by women essentially acts as an invisible subsidy in the health care system.

In the health care workforce, women are not able to practice to their full capacity. Although a growing proportion of physicians worldwide are women, many institutions lack policies that support women as clinicians and leaders or help them integrate professional and family roles. Women are less likely to complete a residency, work full time, or take a leadership role. Gender disparities persist in academia, too, where underrepresentation in research can stall research and policies that could improve women's health. The smaller number of women in leadership positions and a lack of supportive policies are part of a cycle that also leads to women having fewer opportunities for publication and smaller grants.

Advances in promotion of women and health are often led by women at the community level. For example, an initiative for smoke-free public housing, led by local resident Meena Carr out of concern for a grandson with asthma, was implemented by the Boston Public Health Commission and is now a national model.

The commission report provides four recommendations for recognizing women's contributions and otherwise advancing women's health. The new vision of women and health includes a broad accounting of women's contributions and needs in policy and governance to better provide for health and wellbeing.

## Monitoring Progress in Women and Health: Are Morbidity and Mortality Rates Enough? <br> Afaf Ibrahim Meleis, Ph.D., FAAN, Professor of Nursing and Sociology and Dean Emeritus, University of Pennsylvania School of Nursing, and co-chair of the Commission on Women and Health, invited attendees to envision what women's status would be if their caregiving roles were acknowledged and supported. She elaborated on the commission's four key recommendations for moving toward a fuller accounting of women and health:

- Value women. Valuing and acknowledging women wherever they are is a concept that supports the creation of an environment where women can live at their full capacity. The act of valuing women goes beyond universal access to health care and recognizes women's paid and unpaid contributions to health. Providing such an environment could mean, for example, making a breastfeeding or pumping room available. Another aspect could involve building urban environments that are safe, are walkable, and have convenient stores that provide healthy
food - better environments for healthy families. It is important to think of all of women's roles and responsibilities when addressing women's health.
- Count women. This simple but important concept acknowledges that a problem cannot be solved until its size is known. For example, an understanding of the number of women faculty and how their salaries compare with men's has motivated advances in hiring, promoting, and retaining women in academia. Counting the number of girls who are born can help identify where they are neglected in the first months of life. Counting vulnerable women - such as child brides and other trafficked women or women in prisons or shelters - is the first step toward acknowledging their circumstances and creating an environment that enhances their health.
- Compensate women. Women should be compensated fairly for the work they do - including work that is not already counted. Economists have estimated the value of women's paid and unpaid contributions at $\$ 2.26$ trillion. Compensation is also important in light of the links between education, socioeconomic status, and health. There have been efforts to deconstruct and redefine the concept of women's work more broadly as a new basis for research.
- Be accountable to women. ORWH's work is a good example of effort that affects productivity for women and societies by taking action to reduce or eliminate gender inequities, address women's rights to wellness, and ensure effective use of health resources. But more work remains to be done. Just as sex as a biological variable became part of the lexicon, now gender must get the attention it is due.

In addition, morbidity and mortality data are a narrow definition of women and health; they do not reflect the full lifespan, caregivers' well-being, or social determinants of health. A valuation of women's many roles across the lifespan and what would enable them to function at their full capacity in each of these roles would indicate progress.

Developing a framework that measures the report's four recommendations is a priority, and there are reasons to be hopeful that changes are occurring: In 2015, Congress introduced the RAISE Family Caregivers Act, and equal pay legislation has been advanced at the national and state levels. Apps and other technological approaches to improving women's safety or addressing inequalities are also important signs that attention is being paid to women and their concerns.

## Understanding the Health Disadvantage of U.S. Women

Jennifer Karas Montez, Ph.D., Assistant Professor of Sociology, Gerald B. Cramer Faculty Scholar of Aging Studies, Syracuse University, revealed a startling picture of declines in U.S. women's health, with a series of data about trends in U.S. mortality rates.

Between 1992 and 2006, mortality rates for women rose in about 43 percent of U.S. counties. Approximately half of the variation between counties can be attributed to the state the county is in. On the whole, men's life expectancy in the United States is still rising, while women's is falling. In fact, since 1990, differences in women's life expectancies between states have grown.

The data indicate that at age 50, women in the United States can expect to live at least another 30 years. However, the difference in women's life expectancies at 50 varies by more than four years
between states. That difference is larger than the difference between more than 20 high-income nations. Even starker is the disparity in women's life expectancies at birth - from a range of nearly five years among high-income countries to more than seven years among states.

Women's individual differences - in socioeconomic status, education, race, and other factors - receive considerable attention as explanations for these differences. But since women are more likely to be poor and caring for children or parents, state social economic policies have a greater impact on women's lives than on men's. A 2012 Pew Research Center survey found that 61 percent of women have received Social Security, Medicare, Medicaid, food stamps, welfare, and/or unemployment benefits, compared with 49 percent of men. Women are also more likely than men to have received multiple benefits.

In recent decades, state-level social, economic, and health policies have taken different trajectories and had very different impacts on women. States determine minimum wage, requirements for welfare, the Earned Income Tax Credit, and health factors like taxes on cigarettes. Dr. Montez's analysis showed that while about 30 percent of the variation in women's mortality rates among states is due to individual factors, 53 percent is due to state factors - the most important being the economic environment and social cohesion factors such as crime and unemployment rates. For men, individual factors account for 34 percent of differences in mortality rates, and state factors - most significantly tobacco control measures - account for 23 percent. State factors, then, are about twice as important for women's mortality as for men's.

In conclusion, improving U.S. health and longevity - especially that of women - requires changing social and economic policies rather than individual behaviors.

## Discussion

Pearl Eni, NIH Office of the Director, reflected on the magnitude and complexity of the problem that women's health advocates face and asked how the panelists manage pushback and fatigue.

Dr. Meleis said that although raising the same concerns repeatedly can be tiring, she draws inspiration and hope from the examples of progress that she shared. Many people are working at many levels. Fatigue is an unaffordable luxury. Mentoring is also a source of great inspiration and energy.

Jane Kirschling, Ph.D., RN, FAAN, Dean of the University of Maryland School of Nursing, asked whether Dr. Montez had studied how the makeup of state legislative and executive branches might be predictive of the changes in women's mortality rates.

Dr. Montez pointed to a 2017 study in Social Science and Medicine showing a strong correlation between the number of women legislators and improved infant mortality rates. The paper lays out a mechanism for how women's participation in the legislature might change a state's policy focus. Dr. Montez said this study had motivated her to go back and see whether women's participation in the legislature explains outcomes for older women, too. Dr. Meleis added that policies for benefits for women were enacted thanks to the efforts of women legislators.

British Robinson, CEO of the Women's Heart Alliance, asked the panel for recommendations on creating a movement for the fight against cardiovascular disease, the number one killer of women that can match the movement against breast cancer.

Ms. Caglia said good work has been done on framing the health communications message, but more needs to be done. One key is focusing on prevention messaging while making structural changes to the environment. Providers and advocates will need to figure out how to talk about health needs across the life course without pitting conditions against one another.

Lauren Wood, M.D., National Cancer Institute, a speaker at the inaugural NIH Vivian W. Pinn Symposium, noted that there will be an explosion in the number of older women in the next 20 years, as the Baby Boomer generation ages and women continue to live longer than men do. Given the challenges in supporting women's health, she asked the panel for recommendations to blunt trends toward increasing mortality rates among women.

Dr. Meleis noted that a high percentage of people over age 75 in urban areas are women living alone. Women tend to take care of their family members and are left with no one to take care of them. This reality is not being adequately addressed. However, community care centers are one example of a model for addressing this trend. In many cities, women are organizing villages among themselves to provide support and care. Offering resources and policies to support these efforts is an important objective. Sweden and Norway do this well. In addition, more gerontology nurses will be needed.

Victoria Ann Cargill, M.D., M.S.C.E., ORWH, drew attention to the growing number of women who have cared for their mothers and seen them pass away, and she asked how their grief and anger can be tapped.

Dr. Meleis said she was reminded of the situation for families in Botswanan communities devastated by HIV, where the younger generation is left to care for siblings and HIV-infected adults. In addition to dealing with grief and loss, these people are taking on responsibilities beyond their age. The government has begun to provide resources. The first steps are to recognize the issue and then address it with policies, resources, and benefits. Dr. Meleis asked Dr. Cargill for her impressions and thoughts on what we should be doing.

Dr. Cargill said that as health outcomes worsen, it is important to think about the ripple effects on the people left behind, who are often overlooked but who can be great allies. They are a common denominator across diseases, conditions, and states and have experienced the consequences. They represent not only the effects of the worsening health crisis for women but also its echo. They could be advocates for change at the state level.

Dr. Pinn raised the possibility of highlighting more positive messages about women's participation in medicine and research to encourage young women on these paths.

- One area to highlight is women's contributions as physicians. The 2007 Institute of Medicine report Beyond Bias and Barriers: Fulfilling the Potential of Women in Academic Science and Engineering includes data that does so.
- Showcasing women's success in obtaining grant funding - which equals or exceeds that of men - could also encourage young women interested in research careers. Although they do not have as many grants as men, women also do not apply as often. However, they do get the same percentage of the funding they ask for.

Ms. Caglia added that studies published in 2017 showing that female physicians deliver higher-quality care - as reflected in both patients' reports of their experiences and health outcomes - would offer a valuable update to the presentation.

## Closing Remarks

Dr. Clayton noted that the day's presentations had the potential to deeply affect women's health. She urged attendees to promote change in their own spheres of influence. Too often, women's health is left out, but it should be an integral part of every conversation.

