# In the Shadow of Race: Women of Color in Health Disparities Policy

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#### INTRODUCTION

At various times, federal health policy has taken aim at reducing the role of racism and patriarchy in health and health care. For the most part, it has done so by treating racism and patriarchy as separate targets. Until recently, most federal initiatives that have addressed the health needs of women of color have done so incidentally, not expressly. Women of color, in other words, have not figured significantly on the federal health agenda.

In broad terms, the health arenas that racism and patriarchy mediate include biomedical research, health care access, and quality of care. Federal initiatives have sought to intervene in each of these arenas. For example, federal efforts have required the inclusion of women in clinical trials, conditioned federal funding on racial desegregation of hospitals, and, more recently, provided guidelines for culturally and linguistically appropriate services in health care. Each of these arenas, in turn, has implications for health status. The state of one's health, or one's group's health, is partly a function of the availability of biomedical knowledge, access to health care, and the quality of care received.

Critical Race Feminism's two most basic insights tell us that antiracist and feminist projects that fail to explicitly examine the synergistic effects of racism and patriarchy tend to default to androcentrism and white privilege, respectively, and that any gains these projects achieve fail to trickle down to women of color. In the context of health care, the core failure — inattention to the intersections of categories used for social ordering — leaves the particular ways that racialized patriarchy allocates health risks to women of color out of sight and out of mind. In practice, the inattention means that health needs particular to women who are African American, Latina, Native American, Native Alaskan, Pacific Islander, and Asian American will receive less attention and fewer resources than other members of society.

Tracking the history of the federal government's efforts to intervene in the operation of racism and patriarchy in health care shows that these efforts were limited and very much of their times. Each period's initiatives used the then-dominant antidiscrimination paradigm. For example, antiracist efforts in the 1960s focused on racial desegregation, a key goal of that era's fight for civil rights. More importantly, for purposes of this analysis, the history shows that federal initiatives to reduce the role of racism and patriarchy have been almost wholly

separate and that the health needs of women of color have, in fact, remained largely out of sight and out of mind.

In the 1990s, the federal government launched a series of initiatives aimed at "health disparities," or population-based differences in health status and health care. The health disparities initiatives ostensibly aimed to reduce differences by "race, ethnicity, gender, education or income, disability, geographic location, and sexual orientation." Many hoped that the multi-axis approach to disparities would prompt a deep examination of how sociopolitical differences allocate health risks among us, and that the examination would yield an understanding of how those differences operate as markers "for differential exposure to multiple disease-producing social factors" both inside and outside the health system. That kind of critical approach would place women of color, as well as many other groups, on the federal health agenda.

The historical examination and a critical analysis of the disparities approach show that three limitations have thus far stymied the promise of developing a multi-axis approach to health disparities. In the 1990s, the disparities approach focused on data-based differences in health status by race and gender. There was relatively little effort to gather data on other potential sociopolitical bases for health disparities, or to examine the role of discrimination as a contributing factor to health disparities. As a result, other explanations, such as biological race, socioeconomic status, and "lifestyle" became the prevailing explanations for statistical differences in morbidity and mortality among racial groups. Even less effort was made to account for health disparities particular to women of color because they appeared primarily as a statistical subcategory of race. More recently, policy makers have recognized that racism is a significant contributor to health disparities among racial groups. At the same time, however, the scope of the inquiry into health disparities seems to be narrowing. Race is becoming the sole focal point. The narrowing scope of the health disparities inquiry threatens to constrain the understanding of health, as well as to push the health needs of women of color and others back into the shadows.

Finally, to the extent that the disparities efforts acknowledge racism's

<sup>&</sup>lt;sup>1</sup> See 1 U.S. DEP'T OF HEALTH AND HUMAN SERVS., HEALTHY PEOPLE 2010, 11 (2000), available at http://www.healthypeople.gov/document/tableofcontents.htm [hereinafter HEALTHY PEOPLE 2010].

<sup>&</sup>lt;sup>2</sup> David R. Williams & Pamela Braboy Jackson, *Social Sources of Racial Disparities in Health*, 24 HEALTH AFF. 325, 325 (2005).

role in creating health disparities, the understanding of how racism operates and the proposals to reduce health disparities have been primarily structuralist. They focus on organizational structures, practices, and the formal and informal rules of health care institutions. Accounts of how racism affects health care access and quality of care acknowledge the complex, interactive nature of stereotyping and lead to proposals for organizational change, such as affirmative action, to eliminate the problems. While structuralist analysis is good at identifying opportunities for legal intervention, an exclusive focus on health care organizations and practices fails to fully account for how orders of power formed by racialized patriarchy can persist despite the dismantling of specific institutional structures and practices.

Critical analysis of cultural formation sheds light on this phenomenon. As many others have shown, critical cultural inquiry is sensitive to multi-axis difference, differential subordination, and the fact that ideology, including racialized patriarchy, adapts quickly to structural change. Critical theory's attention to ideology allows for a more nuanced and complicated understanding of how inequality becomes embedded in our understanding of "health."

In Part I, I track the federal government's initiatives to reduce the role of racism and patriarchy in health care from the 1940s to the 1970s. I focus on the ways in which race and gender differences have been framed within federal health policy and the resulting inattention to the health needs of women of color. In Part II, I describe the federal government's return to examining the role of difference in health care in the mid-1980s and the subsequent emergence of a "health disparities" The new disparities paradigm focused on approach to that work. quantifiable health status differences among sociopolitical population groups. I argue that the tendency to decontextualize the data de-linked race from racism and thus precluded that work from providing a substantial account of health disparities. In addition, while the disparities approach held the potential to develop a multi-axis approach to the role of difference in health care, the commitment to examining anything other than the role of race wavered. As a result, women's health initiatives and minority health initiatives have remained largely Part III tracks the most recent shift from an separate endeavors. understanding of "disparities," in which racism and patriarchy received little attention as explanations, to an emerging understanding which recognizes racism as a significant contributor to health disparities. I argue that despite the necessity of re-linking race and racism in disparities research, the disparities work is still hampered by the past. The analysis of racism remains primarily structuralist, and race seems to be the only axis of difference at issue in disparities research. I describe the resulting proposals for institutional change and argue that the resulting structuralist discourse, as well as the near-exclusive focus on race, may inhibit efforts to place the health needs of those not privileged in the categories of "race" and "gender" on the national health agenda. In Part IV, I sketch an analytical approach that combines the strengths of structuralism and critical cultural inquiry. This approach holds greater potential than structuralism alone to deepen understanding of the roles that difference plays in health and health care, and to move beyond the traditional race-only civil rights analysis in health care.

# I. THE FEDERAL GOVERNMENT'S ROLE IN ADDRESSING RACISM AND PATRIARCHY IN HEALTH CARE: 1940s-1970s

Federal efforts to address the role of racism and patriarchy in health care have been sporadic, limited, and largely separate. From the 1940s to the late 1960s, the Truman, Kennedy, and Johnson administrations took steps to end de jure racial segregation, including racial segregation in health care. In the 1970s, the women's health movement became an influential component in the women's rights movement, but did not succeed in putting women's health on the federal health agenda. Neither the efforts to desegregate health care nor the women's health movement substantially addressed the status or the health needs of women of color.

#### A. The Federal Government's Influence

The federal government is the most significant actor in the national-level effort to reduce inequalities in health care.<sup>3</sup> State governments and nongovernmental participants, including insurers, can do much to reduce inequalities that impair health care.<sup>4</sup> Yet, a combination of

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<sup>&</sup>lt;sup>3</sup> See also Nicole Lurie, Minna Jung & Risa Lavizzo-Mourey, Disparities and Quality Improvement: Federal Policy Levers, 24 HEALTH AFF. 354, 354 (2005) (advocating for use of quality improvement framework, implemented by Department of Health and Human Services and related agencies, to reduce racial and ethnic health care disparities).

<sup>&</sup>lt;sup>4</sup> See Marsha Lillie-Blanton & Catherine Hoffman, The Role of Health Insurance Coverage in Reducing Racial/Ethnic Disparities in Health Care, 24 HEALTH AFF. 398, 406 (2005); David R. Nerenz, Health Care Organizations' Use of Race/Ethnicity Data to Address Quality Disparities, 24 HEALTH AFF. 409, 410 (2005); Amal N. Trivedi et al., Creating a State Minority Health Policy

funding and regulatory power enhances the federal government's direct and indirect influence on health care. The federal government is the biggest payer of health care services. These services include programs that provide care for half of the nation's racial minorities. The Department of Health and Human Services and related agencies provide oversight for much of the access to and quality of health care in the United States. The federal government is a major funding source for biomedical research and has the accompanying regulatory authority over health care access and quality. In addition, history shows that the government has experience in addressing inequality in health care. As a result, the federal government has unparalleled direct and indirect influence over health care policy and practice.

# B. Racism in Health Care: The Civil Rights Era<sup>8</sup>

In the mid-twentieth century, the dominant framework for addressing racism was desegregation of society's most essential institutions, including health care facilities. The Truman, Kennedy, and Johnson administrations made serious efforts to desegregate health care. Their efforts, like most efforts in the civil rights movement of that time, aimed at race- and class-based exclusions, but paid little attention to the particularized experiences of women of color. By the late 1960s, the federal government had pulled back from its efforts to desegregate health care.

Federal efforts to end racially segregated health care date back to the 1940s. The Hill-Burton Act and Title VI of the Civil Rights Act of 1964 were key tools in those efforts. Congress enacted the Hill-Burton Act to provide federal funding for hospital construction. The law mandated nondiscrimination by providing that a "hospital or addition . . . will be made available to all persons residing in the territorial area of the applicant without discrimination on account of race, creed, or color." However, a provision immediately following the nondiscrimination

Report Card, 24 HEALTH AFF. 388, 393 (2005).

<sup>&</sup>lt;sup>5</sup> See Medicare and Medicaid Programs: Hospice Conditions of Participation, 70 Fed. Reg. 30,840 (May 27, 2005) (to be codified at 42 C.F.R. pt. 418).

<sup>&</sup>lt;sup>6</sup> Lurie, Jung & Lavizzo-Mourey, *supra* note 3, at 356.

<sup>&</sup>lt;sup>7</sup> See id.

<sup>&</sup>lt;sup>8</sup> For a detailed account and analysis of the role of racial segregation in health care, see DAVID BARTON SMITH, HEALTH CARE DIVIDED: RACE AND HEALING A NATION (1999).

<sup>&</sup>lt;sup>9</sup> Hospital Survey and Construction Act, Pub. L. No. 79-725, § 622(f), 60 Stat. 1040, 1043 (1946) (codified as amended at 42 U.S.C. § 291e).

mandate made "an exception . . . in cases where separate hospital facilities are provided for separate population groups, if the plan makes equitable provision on the basis of need for facilities and services of like quality for each such group." Thus, the Hill-Burton Act funded and thereby enabled racially segregated facilities. Hospitals, particularly those in the South, took advantage of the separate but equal provision by maintaining racially segregated facilities. In 1948, President Truman took a much less ambivalent stance on desegregation. executive orders<sup>12</sup> that most associate with desegregating the military. The same orders forced federal health facilities, including the Veterans Administration, to desegregate. Because the vast majority of United States residents did not use federal health facilities, these orders had more political significance than direct impact on health care. The federal government played its most significant role in reducing inequality in health care in the 1960s. In 1963, the Fourth Circuit held the "separate but equal" provision of the Hill-Burton Act unconstitutional in *Simkins v*. Moses H. Cone Memorial Hospital. In the spring of 1964, the Department of Health Education and Welfare revised the Hill-Burton regulations according to the Simkins holding. 15 During the summer of 1964, Congress enacted both a five-year extension of the Hill-Burton Act without the "separate but equal" provision and Title VI of the 1964 Civil Rights Act, which prohibited racial discrimination by facilities that accept federal money and established the Office of Equal Health Opportunity to carry out Title VI's mandates.<sup>11</sup>

Initially, Title VI proved to be a weak tool for desegregating health care because relatively few facilities received federal money.<sup>18</sup> Then, in 1966, President Johnson insisted that no hospital could enroll in the thennew Medicare program unless the hospital provided assurance of

<sup>10</sup> Id.

<sup>&</sup>lt;sup>11</sup> SMITH, *supra* note 8, at 47.

<sup>&</sup>lt;sup>12</sup> Exec. Order No. 9981, 13 Fed. Reg. 4313 (July 26, 1948); Exec. Order No. 9980, 13 Fed. Reg. 4311 (July 26, 1948).

<sup>&</sup>lt;sup>13</sup> For a broader account of Executive Orders 9980 and 9981, see MICHAEL R. GARDNER, HARRY TRUMAN AND CIVIL RIGHTS: MORAL COURAGE AND POLITICAL RISKS 105-21 (2002).

<sup>&</sup>lt;sup>14</sup> Simkins v. Moses H. Cone Mem'l Hosp., 323 F.2d 959, 969 (4th Cir. 1963).

<sup>&</sup>lt;sup>15</sup> SMITH, *supra* note 8, at 106-07.

<sup>&</sup>lt;sup>16</sup> *Id.* at 107.

<sup>17</sup> See id. at 143-59.

<sup>&</sup>lt;sup>18</sup> Sidney D. Watson, *Race, Ethnicity and Quality of Care: Inequalities and Incentives*, 27 Am. J.L. & MED. 203, 214 (2001).

compliance with Title VI.  $^{19}$  A substantial percentage of the U.S. hospitals had been racially segregated, particularly in the South.  $^{20}$  By July 1, 1966, the launch date for Medicare, 92% of hospitals in the United States had officially desegregated.  $^{21}$ 

President Johnson's insistence on using Medicare funding as leverage to desegregate hospitals did substantially reduce the most obvious form of racism in health care. It did not eliminate racism in health care.<sup>22</sup> It did not even eliminate segregated health care facilities.<sup>23</sup> From the late 1960s, however, the government began what health care scholar David Barton Smith has characterized as "the federal retreat" from civil rights enforcement in health care.<sup>24</sup> This happened despite the best efforts of the Office of Equal Health Opportunity staff. In the absence of federal initiative, the burden of reducing racial inequities in health care fell primarily on civil rights organizations such as the NAACP,<sup>25</sup> public health advocates,<sup>26</sup> and individual providers.<sup>27</sup> Efforts to eliminate racist

<sup>&</sup>lt;sup>19</sup> SMITH, *supra* note 8, at 128-42.

 $<sup>^{20}</sup>$  *Id.* at 134. For an account of the black community's response to exclusion, see Vanessa Northington Gamble, Making a Place for Ourselves: The Black Hospital Movement 1920-1945 (1995).

<sup>&</sup>lt;sup>21</sup> Watson, *supra* note 18, at 215. This was more than a decade after *Brown v. Board of Education*. 347 U.S. 483 (1954).

<sup>&</sup>lt;sup>22</sup> David Barton Smith, Eliminating Disparities in Treatment and the Struggle to End Desegregation, in COMMONWEALTH FUND, PUBLICATION NO. 775, at 7 (2005) [hereinafter Smith, Eliminating Disparities]; see also David Barton Smith, Racial and Ethnic Disparities and the Unfinished Civil Rights Agenda, 24 HEALTH AFF. 317, 320-23 (2005) (describing examples of limitations of desegregation effort, including continued segregation of blood supply in Louisiana, "white flight" of hospitals from inner-city locations to mostly white suburbs, and 1966 Health Education and Welfare Department decision to exempt physician participants in Medicare from Title VI compliance).

<sup>&</sup>lt;sup>23</sup> Ruqaiijah Yearby, *Striving for Equal Access and Quality, but Settling for the Status Quo: Is Title VI More Illusory Than Real*, 9 DEPAUL J. HEALTH CARE L. (forthcoming 2006) (draft on file with author).

<sup>&</sup>lt;sup>24</sup> SMITH, *supra* note 8, at 143; *see also* Smith, *Eliminating Disparities*, *supra* note 22, at 7 ("Since 1968, providers have been insulated from any effective, external Title VI accountability for their federal Medicare and Medicaid funds . . . . The Office for Equal Health Opportunity was disbanded in 1968 and its Title VI certification responsibilities were shifted to the new, centralized Office for Civil Rights in DHEW. For the next critical decade, that office shifted resources to address the issue of school desegregation.").

<sup>&</sup>lt;sup>25</sup> See Marianne Engelman Lado, Unfinished Agenda: The Need for Civil Rights Litigation to Address Race Discrimination and Inequalities in Health Care Delivery, 6 Tex. F. on C.L. & C.R. 1, 16-26 (2001).

<sup>&</sup>lt;sup>26</sup> See, e.g., Am. Pub. Health Ass'n, Community Solutions to Health Disparities Database, http://www.apha.org/NPHW/solutions/index.cfm (last visited Oct. 20, 2005). This searchable database provides "information about [community] programs and initiatives that are working to address the problem of health disparities." *Id.* Many of

health care remained in the trenches for the next thirty years.

# C. Patriarchy in Health Care: The Women's Health Movement and the Abortion Wars

While the Kennedy and Johnson administrations coordinated with civil rights organizations to address racial segregation in health care, they made few corresponding efforts to address patriarchy in health care during the same period. In the 1970s, however, the period of federal retreat from enforcing civil rights laws, the women's health movement gained visibility and influence. That influence made little impact on federal health policy. Federal laws continued to provide for prenatal care and other services directly related to women's role as childbearers. Courts issued decisions in abortion cases. But the push for a broader understanding of women's health and to eliminate patriarchy in health care remained in the hands of nongovernmental organizations and activists.

Broadly speaking, the women's health movement during this period generated a radical feminist discourse about women's health that sought to challenge patriarchy in medicine by making self-help feasible for women. The movement's strategies focused on: acknowledging and sharing women's experiences of health, illness, and sexuality; arming women with knowledge, particularly knowledge about women's sexual and reproductive functions; resisting the highly medicalized standard practices for childbirth; and creating women's health centers. The women's health movement challenged the medical profession's paternalistic views about women's decisionmaking capacity, and medical standards that prioritized physician control over patient autonomy. It also sought to expand the definition of "women's health" to include aspects of well-being beyond a woman's childbearing capacity.

The publication of *Our Bodies, Ourselves* is probably the most iconic achievement of that period. The women who published that book aimed

<sup>27</sup> For example, Dr. Jean Cowsert took the initiative to desegregate the Mobile Infirmary in Alabama in the late 1960s. For an account, see SMITH, *supra* note 8, at 154-58.

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these programs were established in response to the federal retreat from civil rights.

<sup>&</sup>lt;sup>28</sup> Elizabeth Fee, Women and Health Care: A Comparison of Theories, in WOMEN AND HEALTH: THE POLITICS OF SEX IN MEDICINE 23-26 (Elizabeth Fee ed., 1982).

<sup>&</sup>lt;sup>29</sup> Fee, *supra* note 28, at 24-25; Judy Norsigian, *The Women's Health Movement in the United States, in* MAN-MADE MEDICINE: WOMEN'S HEALTH, PUBLIC POLICY, AND REFORM 79, 80-84 (Kary L. Moss ed., 1996) [hereinafter MAN-MADE MEDICINE].

to create a "self-health women's movement."<sup>30</sup> They provided information about women's health to women — information that was simply not available elsewhere. During the same decade, breast cancer advocacy became politicized. Shirley Temple Black, Betty Ford, and Happy Rockefeller publicly announced their breast cancer diagnoses. In 1977, Rose Kushner's book, *Why Me?*, recounting her battle with breast cancer and challenge to medical authorities over then-standard practices,<sup>31</sup> was published.

To some extent, the movement sought to challenge the narrow, patriarchal definition of "women's health" in national health policy. For example, the National Women's Health Network formed in 1975 "to give women a greater voice within the health care system." However, despite its broad vision, the movement's effects on federal health policy were relatively discrete. To the extent that federal law addressed women's health, it did so primarily in the context of public health benefits. While important, those benefits — for prenatal and neonatal care — "revolved around women's roles as bearers and caregivers of children" and ignored women's broader health needs. "

It was only in the context of the abortion debate that a woman's control over her own health became a federal issue. During the 1970s

Molly M. Ginty, Our Bodies, Ourselves *Turns 35 Today*, Women's E News, May 4, 2004, http://www.womensenews.org/article.cfm/dyn/aid/1820/context/archive. The group initially wrote and self-published a 138-page booklet called *Women and Their Bodies*. In response to the overwhelming success of the booklet, they formed the Boston Women's Health Collective and published a 276-page version, *Our Bodies*, *Ourselves*, in 1973. *Id*.

<sup>&</sup>lt;sup>31</sup> For further discussion of the role that Kushner and the Women's Health Movement played in changing breast cancer medical practice, see Norsigian, *supra* note 29, at 79, 85.

<sup>&</sup>lt;sup>32</sup> For additional information about NWHN, see http://www.womenshealthnetwork.org/about/index.php (last visited Aug. 15, 2005). *See also* DEP'T OF HEALTH AND HUMAN SERVS., A CENTURY OF WOMEN'S HEALTH 1900-2000, at 30 (2002).

<sup>&</sup>lt;sup>33</sup> Susan L. Waysdorf, Fighting for Their Lives: Women, Poverty, and the Historical Role of United States Law in Shaping Access to Women's Health Care, 84 KY. L.J. 745, 767 (1995-96).

<sup>&</sup>lt;sup>34</sup> See Brietta R. Clark, Erickson v. Bartell Drug Co.: A Roadmap for Gender Equality in Reproductive Health Care or an Empty Promise?, 23 LAW & INEQ. 299, 325-26 (2005). Congress did enact two major laws that affected women's health — the Hyde Amendment, Pub. L. No. 94-439, § 209, 90 Stat. 1418, 1434 (1976), which banned the use of federal Medicaid funds for abortion services and the Pregnancy Discrimination Act, which amended Title VII to prohibit sex discrimination in employment on the basis of pregnancy, childbirth, or related medical conditions. Pregnancy Discrimination Act, 40 Pub. L. No. 95-555, 92 Stat. 2076 (1978) (codified as amended at 42 U.S.C. 2000(e)(k) (2005)).

The focus on pregnancy in both laws indicates that despite the women's health movement, the federal approach to women's health remained narrowly defined by biological essentialism.

and 1980s, the debate took place in Congress, the courts, and the state legislatures.<sup>35</sup> In most of the battles, however, the government sought to impose restrictions on a woman's right to decide. There were few, if any, federal initiatives to eliminate patriarchy in health care and certainly none that paralleled the federal government's efforts in the 1960s to eliminate racial segregation in health care.

# D. Women of Color

The limited federal benefits for prenatal and neonatal care did provide many low income women of color with access to necessary health care. At the same time, racialized stereotypes of "welfare mothers" made use of the benefits by women of color both visible and stigmatized.<sup>36</sup> Thus, the only place on the federal health agenda in which women of color appeared was perceived in negative terms.

In the nongovernmental arena, the right to decide became a defining issue for the mainstream women's rights movement. This had at least two negative effects. The equation between abortion and gender equality ignored the fact that for women of color, immigrant women, and low-income women, abortion restrictions were only one of many types of reproductive control they experienced and that reproductive control was only one of many types of subordinations they experienced. In addition, the keyhole focus that abortion brought to the fight for gender equality seemed to constrain the understanding of women's health. Providing access to safe abortions became the core of "women's health." As a result, the biological essentialism that characterized the federal approach to women's health also pervaded the mainstream women's rights approach to women's health.

In the 1980s, women of color challenged the mainstream women's rights movement on two related grounds — the focus on abortion to the exclusion of other forms of reproductive control that heavily impact women of color and the failure to include the experiences of women of color in the fight for gender equality. They made some progress in nongovernmental organizations, largely by organizing outside of the

<sup>&</sup>lt;sup>35</sup> See Kathryn Kolbert & Andrea Miller, Legal Strategies for Abortion Rights in the Twenty-First Century, in Abortion Wars: A Half Century of Struggle, 1950-2000, at 96-97 (1998).

<sup>&</sup>lt;sup>36</sup> DOROTHY E. ROBERTS, KILLING THE BLACK BODY, 17-19, 207-08 (1997); Lisa C. Ikemoto, *The In/Fertile, the Too Fertile, and the Dysfertile*, 47 HASTINGS L.J. 1007, 1047-52 (1996).

mainstream movement.<sup>37</sup> The federal health agenda, however, remained based on a normative white male standard for "health" that continued to define women's health primarily in terms of childbearing capacity. As a result, advocacy for an understanding of women's health that did not rest on biological and racial essentialism remained largely in the margins of the women's rights movement.

#### II. THE SHIFT TO DISPARITIES

In the late twentieth century, the first stages of a sea-change in federal health policy took place. The government acknowledged that the health policy and research agenda centered around the interests of white men. Separate Task Forces on Black and Minority Health and on Women's Health Issues called for a wide range of efforts to address bias in health care. Early 1990s efforts used an affirmative action-like approach to addressing the white privilege and androcentrism reflected in federal health policy and research, requiring the inclusion of women in clinical trials and the expansion of race-based health data collection. At the same time, the Task Force recommendations to address other forms of bias that affect health care access and quality were largely left ignored.

By the late 1990s, the government had apparently embraced a health disparities framework that used the data collection efforts to identify measurable health status differences among populations. The disparities efforts on race and gender finally seemed poised to converge. Federal health policy might finally begin an explicit examination of the effects of racialized patriarchy on health care and, in particular, on the health care of women of color. However, the acontextualized use of race, sex, and other sociopolitical categories left the ways that racism and patriarchy

<sup>&</sup>lt;sup>37</sup> For example, the Black Women's Health Project formed in 1981 with a mission to promote optimum health for Black women across their lifespans. Renamed the Black Women's Health Imperative in 2003, the organization focuses its efforts on community outreach, advocacy, resources and research, and education. See Black Women's Health Imperative Home Page, http://www.blackwomenshealth.org (last visited Jan. 30, 2005). In 1989, Asian American women in California organized as "Asians and Pacific Islanders for Choice" in order to add the voices of Asian and Pacific Islander women to the pro-choice movement. Very shortly after, they renamed the organization "Asians and Pacific Islanders for Reproductive Health" to reflect their more expansive understanding of the issues at stake for women in their communities. More recently, the organization has changed its name to "Asian Communities for Reproductive Justice" to reflect the fact that it uses a progressive social justice analysis to challenge the many ways in which racialized patriarchy produces social controls that impact the reproductive freedom of Asian American women.

affect health care untouched.

#### A. The 1985 Task Force Reports

In 1985, two reports marked the beginning of the shift. The Department of Health and Human Services Task Force on Black and Minority Health issued a report that identified the lack of race-specific health data<sup>38</sup> and the lack of racial minorities in health care as providers as contributing factors to access and quality of care disparities.<sup>39</sup> In the same year, a Public Health Service Task Force on Women's Health Issues published a report.<sup>40</sup> Among the recommendations was the inclusion of women in clinical trials,<sup>41</sup> research to examine the social and cultural bases for differential care, and an admonition to make other efforts to address gender bias in health care.<sup>42</sup> Both reports used "disparities" to characterize race- and gender-based differences in access and quality of care, but "bias" was the watchword.

The impact of the Task Force Reports was hampered by two problems. The first was substantive. Neither Report expressly called attention to

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<sup>&</sup>lt;sup>38</sup> U.S. DEP'T OF HEALTH AND HUMAN SERVS., REPORT OF THE SECRETARY'S TASK FORCE ON BLACK AND MINORITY HEALTH 31-33 (1985), available at http://www.omhrc.gov/templates/browse.aspx?lvlID=13 [hereinafter REPORT OF THE SECRETARY'S TASK FORCE]. During the same year, another report acknowledged that most health status reports collected and sorted data into two main groups — white and nonwhite. U.S. DEP'T OF HEALTH & HUMAN SERVS., HEALTH STATUS OF MINORITIES AND LOW INCOME GROUPS 9 (1985). The report recommended collecting health data and reporting race and ethnic specific data in order to address "the health of the disadvantaged." *Id.* 

<sup>&</sup>lt;sup>39</sup> REPORT OF THE SECRETARY'S TASK FORCE, *supra* note 38, at 21-22 (1985).

<sup>&</sup>lt;sup>40</sup> The report was based on a series of regional meetings to gather perspectives on women's health and on a national symposium on women's health. U.S. DEP'T OF HEALTH AND HUMAN SERVS., PUB. HEALTH SERV., I REPORT OF THE PUBLIC HEALTH SERVICE TASK FORCE ON WOMEN'S HEALTH ISSUES 89-101 (1985).

<sup>&</sup>lt;sup>41</sup> For analysis of the extent and effects of excluding women from clinical trials, see Francoise Baylis et al., *Reframing Research Involving Humans*, in THE POLITICS OF WOMEN'S HEALTH: EXPLORING AGENCY AND AUTONOMY 237-46 (Susan Sherwin coordinator, 1998); R. Alta Charo, *Protecting Us to Death: Women, Pregnancy, and Clinical Research Trials*, 38 ST. LOUIS U. L.J. 135 (1993); Editorial, *Gender Disparities in Clinical Decisionmaking*, 266 JAMA 559 (1991); Vanessa Merton, *The Exclusion of Pregnant, Pregnable, and Once-Pregnable People (A.K.A. Women) from Biomedical Research*, 3 TEX. J. WOMEN & L. 307, 369 (1994); Karen H. Rothenberg, *Gender Matters: Implications for Clinical Research Momen's Health Care*, 32 HOUS. L. REV. 1201 (1996); Jeri Altneu Sechzer et al., *Sex and Gender Bias in Animal Research and in Clinical Studies of Cancer, Cardiovascular Disease, and Depression, in FORGING A WOMEN'S HEALTH RESEARCH AGENDA: POLICY ISSUES FOR THE 1990s, at 21-48 (Jeri A. Sechzer et al. eds., 1994).* 

 $<sup>^{\</sup>rm 42}~$  U.S. Dep't of Health and Human Servs., Pub. Health Serv., II Report of the Public Health Service Task Force on Women's Health Issues 2 (1985).

the potential overlap between "Black and Minority Health" and "Women's Health." In other words, neither report addressed the possibility that bias might impair or enhance the health care of Black women, for example, differently than that of Black men or nonblack women. The second problem was political. The reports attracted attention. Resources and action, however, were slow to follow.

The action that the Task Force Reports produced reflected both problems. For example, in response to a Task Force Report recommendation, the Department of Health and Human Services established the Office of Minority Health ("OMH"). The stated mission of the OMH was "to improve and protect the health of racial and ethnic minority populations through the development of health policies and programs that will eliminate health disparities." The OMH's mandate did not include the goal of attending to how gender difference impacts health care among racial and ethnic minorities. In addition, while it seemed the federal government was once again a player in the effort to eliminate inequality in health care, Congress failed to fund the OMH's efforts for the next five years. Without resources, the OMH could not implement other Task Force Report recommendations.

Similarly, in 1986, the National Institutes of Health ("NIH") responded to one recommendation the Task Force on Women's Health had made. The NIH established an Advisory Committee on Women's Health Issues and adopted a policy that "urged grant applicants to consider the inclusion of women in the study populations of all clinical research efforts," asked researchers to evaluate sex differences in their studies, and required a clear rationale for excluding women. <sup>45</sup> The policy did not require the inclusion of women of color. Despite the policy, a 1990 General Accounting Office Report revealed that the NIH had made little progress in implementing it. <sup>46</sup>

<sup>&</sup>lt;sup>43</sup> 42 U.S.C. § 300u-6 (2005).

<sup>&</sup>lt;sup>44</sup> Dep't of Health and Human Servs., Off. of Minority Health, www.omhrc.gov/OMH/sidebar/aboutOMH.htm (last visited March 22, 2005).

<sup>&</sup>lt;sup>45</sup> National Institutes of Health: Problems in Implementing Policy on Women in Study Populations, Testimony Before the Subcomm. on Health and the Environment, Comm. on Energy and Commerce, 101st Cong. 3-4 (1990) (statement of Mark Nadel, Associate Director, National and Public Health Issues, Human Resource division), available at http://archive.gao.gov/d48t13/141859.pdf.

<sup>&</sup>lt;sup>46</sup> *Id.* at 5-6.

#### B. The Early 1990s Federal Response

In the 1990s, the federal government took more substantive steps toward addressing minority and women's health. As noted, these steps echoed vaguely of an affirmative action-like approach to inclusion. They required conscious inclusion of categories and persons previously excluded by unconscious race and gender preferences — primarily in clinical trials and health data collection. In that way, early 1990s efforts made progress toward achieving the spirit of the 1990s Task Force Reports. Yet, they also repeated the substantive problem of the Task Force Reports. Despite the simultaneous efforts on behalf of racial minorities and women, the efforts prompted little attention to the possibility that nonwhite women might have health issues that differed from those affecting men of color and white women.

For example, in 1990, Congress enacted the Disadvantaged Minority Health Improvement Act<sup>47</sup> and provided the OMH with funding to pursue its mission.<sup>48</sup> The Disadvantaged Minority Health Improvement Act provided that the National Center for Health Statistics move beyond three-category data collection — white/black/other — and instead collect race and ethnic-specific data.<sup>49</sup> For the first time, the federal government began collecting health data sorted for Latinos, Asians, Pacific Islanders and subgroups.<sup>50</sup> These changes addressed the nearly complete dearth of information about the health status of Latina/os,

 $<sup>^{\</sup>scriptscriptstyle 47}\,$  Disadvantaged Minority Health Improvement Act of 1990, Pub. L. No. 101-527, 104 Stat. 2311.

<sup>&</sup>lt;sup>48</sup> *Id*.

<sup>&</sup>lt;sup>49</sup> For further discussion of the federal laws that require or affirm the collection and use of race and ethnicity health data, see MARA YOUDELMAN & STEVE HITOV, RACIAL, ETHNIC, AND PRIMARY LANGUAGE DATA COLLECTION IN THE HEALTH CARE SYSTEM: AN ASSESSMENT OF FEDERAL POLICIES AND PRACTICES (2001).

The 1997 Office of Management and Budget Directive 15 required reporting of federal health statistics using five race categories and one ethnicity category. Revisions to the Standards for the Classification of Federal Data on Race and Ethnicity, 62 Fed. Reg. 58,782 (Oct. 30, 1997). Federal agencies had until 2003 to comply with federal guidelines on race and ethnicity data collection practices that added a "Native Hawaiian and other Pacific Islander" category and allowed respondents to choose more than one race. *Id.* at 58,786. For a critical analysis of Directive 15, see Michael Omi, *Racial Identity and the State: The Dilemmas of Classification*, 15 LAW & INEQ. 7, 11-12 (1997). *See also* Ernest Moy, Elizabeth Dayton & Carolyn M. Clancy, *Compiling the Evidence: The National Healthcare Disparities Reports*, 24 HEALTH AFF. 376, 378-79 (March/April 2005) (explaining data issues that have persisted after change in data collection practices).

Asian Americans and Pacific Islanders, and Native Americans. The switch helped push health policy work out of the black/white paradigm and into a more inclusive multiracial approach.

At the same time, federal initiatives to address women's health unfolded on a track that paralleled but did not intersect with minority health initiatives. The women's health initiatives were two-fold in nature. First, federal efforts to address women's health, like its efforts to address minority health, emphasized data collection and inclusion in clinical trials. This began to move federal health policy away from the use of the white male as the unofficial normative standard for "health." It also produced statistical information about health status differences between males and females. In addition, the women's health initiatives moved a slightly broader understanding of "women's health" onto the federal research agenda for the first time. <sup>51</sup>

Two examples illustrate the twofold approach. The 1990 Health Reauthorization Act established the Office of Research on Women's Health ("ORWH") in NIH<sup>52</sup> in the same year that Congress finally funded the OMH. The 1990 Reauthorization Act charged the ORWH with oversight to ensure that the NIH adopted policy to actually include women in clinical trials.<sup>53</sup> Until then, despite the 1986 policy,

<sup>&</sup>lt;sup>51</sup> The fact that women's health advocates became a recognized force on Capitol Hill in the 1990s may explain the broader approach to women's health. KAREN L. BAIRD, GENDER JUSTICE AND THE HEALTH CARE SYSTEM 137 (1998). The Congressional Caucus for Women's Issues played a significant role in changing federal research policy and establishing the ORWH. Marcia Bayne-Smith, Health and Women of Color: A Contextual Overview, in RACE, GENDER, AND HEALTH 1, 2 (Marcia Bayne-Smith ed., 1996). Women's health advocates also shaped the federal research agenda. For example, in 1991, the NIH launched the Women's Health Initiative, in response to pressure from women's health advocates. BAIRD, supra at 138. The Women's Health Initiative funded a \$628 million study of over 160,000 female clinical participants over 15 years. For a description of the study, see The Women's Health Initiative Study Group, Design of the Women's Health Initiative Clinical Trial and Observational Study, 19 CONTROLLED CLINICAL TRIALS 61 (1998). For feminist critique of the national research agenda during this period, see SUE V. ROSSER, WOMEN'S HEALTH — MISSING FROM U.S. MEDICINE 7 (1994). The federal government also began responding to particular advocacy efforts that began in the 1970s. Breast cancer advocates acquired significant clout. For a general discussion of breast cancer awareness advocacy, see Susan Braun, The History of Breast Cancer Advocacy, 9 BREAST J. S101 (2003); Jill Moffett, Moving Beyond the Ribbon: An Examination of Breast Cancer Advocacy and Activism in the U.S. and Canada, 15 CULTURAL DYNAMICS 287 (2003).

<sup>&</sup>lt;sup>52</sup> S. REP. No. 101-459, at 29 (1990), reprinted in 1990 U.S.C.C.A.N. 4549, 4563.

<sup>&</sup>lt;sup>53</sup> The FDA has been much slower to include women in clinical trials for drug testing. See Jillian Hemstock, Women in Clinical Trials — Where Are They?, 12 BUFF. WOMEN'S L.J. 25, 27-29 (2004). For an analysis of progress made at the NIH and FDA, see Karen L. Baird, The New NIH and FDA Medical Research Policies: Targeting Gender, Promoting Justice, 24 J.

investigators had conducted clinical testing of new drugs nearly exclusively on white males.<sup>54</sup> The 1990 Act also sought to increase the number of women in biomedicine and to include women's health issues on the research agenda. In 1993, Congress reprised this approach with the National Institutes of Health Revitalization Act of 1993. The 1993 Act required the inclusion of racial minorities and women in clinical trials, analyses of subpopulation differences,<sup>55</sup> and additional funding for breast, ovarian, and other reproductive cancers,<sup>56</sup> as well as osteoporosis.<sup>57</sup>

Neither the minority health initiatives nor the women's health initiatives expressly or intentionally omitted women of color. In fact, the race- and ethnicity-based health data included "male" and "female" as subcategories. Similarly, the women's health data included subcategories for race and ethnicity. However, no federal office or agency had a mandate to specifically consider the health statuses or needs of women of color, much less implement health policy that would address the needs of women of color. For example, the 1994 NIH Guidelines on the Inclusion of Women and Minorities as Subjects in Clinical Research did not require the inclusion of women of color. Health education scholar Marcia Bayne-Smith observed the need to include women of color as principal investigators and to locate study sites in communities of color as prerequisites to recruiting women of color in the Women's Health Initiative. But in 1996, she stated: "As of this writing, ORWH does not appear to be making any great strides on any of these steps. Therefore, at the end of this initiative, the likelihood is great that multimillion-dollar clinical trials on women's health will have taken place and U.S. researchers will still have gaps in their

HEALTH POL. POL'Y & L. 531, 531-40 (1999). For analysis of the extent and effects of excluding women from clinical trials, see generally supra note 41.

<sup>&</sup>lt;sup>54</sup> Barbara A. Noah, Racist Health Care, 48 Fl.A. L. Rev. 357, 365-66 (1996); see also Barbara A. Noah, The Participation of Underrepresented Minorities in Clinical Research, 29 AM. J.L. & MED. 221, 224 (2003).

 $<sup>^{55}</sup>$  National Institutes of Health Revitalization Act of 1993, 103 Pub. L. No. 43, § 131, 107 Stat. 122, 133 (codified at 42 U.S.C. § 289a-2 (2005)).

 $<sup>^{56}\,</sup>$  National Institutes of Health Revitalization Act of 1993, 103 Pub. L. No. 43, § 401, 107 Stat. 122, 153 (codified as amended at 42 U.S.C. § 285a-6 (2005)).

 $<sup>^{\</sup>rm 57}$  National Institutes of Health Revitalization Act of 1993, 103 Pub. L. No. 43, § 302, 107 Stat. 122, 151 (codified as amended at 42 U.S.C. § 284e (2005)).

<sup>&</sup>lt;sup>58</sup> For additional commentary on this omission, see Jonathan M. Eisenberg, *NIH Promulgates New Guidelines for the Inclusion of Women and Minorities in Medical Research*, 10 BERKELEY WOMEN'S L.J. 183, 188 (1995).

knowledge base about the health issues of women of color."59

#### C. The Federal Embrace of the Disparities Framework

In the late 1990s, "health disparities" became the watchword of federal health policy. The disparities approach seeks to identify and quantify group-based differences in health status, such as disease incidence and mortality rates. The validity and significance of the disparities approach relies heavily on data — data produced by the initiatives launched in the early 1990s. The disparities framework rests on predefined sociopolitical groups — those identified in the early 1990s initiatives by race, ethnicity, and sex. Within the framework, category comparison is the standard way of evaluating health status.

During this period, federal efforts to address the role of sociopolitical difference in health care largely took a single-axis, race-only approach. For example, President Clinton made "health disparities" a significant component of the President's Initiative on Race. In 1998, he announced the goal of eliminating racial and ethnic health status disparities in six areas. Other Clinton administration initiatives also clearly focused on racial and ethnicity. Each of the control of the president of

<sup>&</sup>lt;sup>59</sup> Bayne-Smith, *supra* note 51, at 3.

<sup>&</sup>lt;sup>60</sup> For an extensive discussion of the widely varying definitions of "disparities," see Moy, Dayton & Clancy, *supra* note 50, at 377.

<sup>61</sup> See Rene Bowser, Eliminating Racial and Ethnic Disparities in Medical Care, 30 SUM BRIEF 24, 25 (2001). Congress followed the administration's lead with the Minority Health and Health Disparities Research and Education Act of 2000. This Act established the National Center for Minority Health and Health Disparities at the National Institutes of Health. It also required the Agency for Healthcare Research and Quality to conduct research on minority health and health disparities and directed the National Academy of Sciences to assess Health and Human Services' minority data collection practices. Minority Health and Health Disparities Research and Education Act of 2000, Pub. L. No. 106-525, § 301, 114 Stat. 2495, 2507 (2000) (codified as amended at 42 U.S.C. § 3501 (2005)). For more information, see National Center on Minority Health and Health Disparities, About NCMHD, http://ncmhd.nih.gov/about\_ncmhd/history.asp (last visited Oct. 20, 2005).

The Health Disparities Collaboratives ("HDC") exists within the Health Resources and Services Administration. The stated goal of the HDC is to "(1) generate and document improved health outcomes for underserved populations; (2) transform clinical practice through new evidence-based models of care; (3) develop infrastructure, expertise, and multi-disciplinary leadership to improve health status; and (4) build strategic partnerships." Health Resources and Servs. Admin., U.S. Dep't of Health and Human Servs., Bureau of Primary Healthcare: Health Disparities Collaboratives, http://bphc.hrsa.gov/quality/Collaboratives.htm (last visited Oct. 20, 2005). REACH is an initiative located within the CDC to carry out the *Healthy People 2010* goal of eliminating racial and ethnic disparities in health. Ctr. for Disease Control, Racial and Ethnic Approaches to Community Health ("REACH"), http://www.cdc.gov/reach2010/ (last

These initiatives did not supersede or limit the laws and programs implemented in the early 1990s to promote women's health. They did, however, shift the emphasis to race and away from other health disparities. The possibility of explicitly examining the health status of, or the interlocking nature of racism and patriarchy and its particular effects on, women of color seemed to dim. The shift to a race-only lens on disparities had other consequences as well.

The shift to disparities initially produced three explanations for data disparities that seemed both quantifiable and apolitical. Biological race, socioeconomic status, and personal responsibility became the three most apparent explanations for racial disparities in health. Each of these explanations is deeply intertwined with racial ideology. <sup>63</sup> But, broadly

visited Oct. 20, 2005). EXCEED (Excellence Centers to Eliminate Ethnic/Racial Disparities) is an initiative within the Agency for Healthcare Research and Quality that supports programs that "analyze underlying causes and contributing factors for racial and ethnic disparities in health care and to identify and implement strategies for reducing and eliminating them." AGENCY FOR HEALTHCARE RES. AND QUALITY, U.S. DEP'T OF HEALTH & HUMAN SERVS., EXCELLENCE CENTERS TO ELIMINATE ETHNIC/RACIAL DISPARITIES (EXCEED), PROGRAM BRIEF (2001), available at http://www.ahrq.gov/research/exceed.pdf.

63 Biological race is the notion that differences among racial populations are inherently biological. The simultaneous revival of biological race in genetic research may have bolstered the use of biological race in disparities research. See Bowser, supra note 61, at 25 ("The delusions about race that persist in the politics of minority health improvement, however, have blinded policy makers to the role of racial bias in medical treatment as a cause of the health disparities that we observe."). Given its historical use as a justification for the political subordination of racial minorities and for eugenic practices, biological race is proving to be the most controversial explanation. Yet, practices such as racial profiling in medicine and race-specific marketing by pharmaceutical companies also suggest that biological race has acquired a foothold as a legitimate science claim.

To the extent that biological race has failed to replace discrimination as the cause of health status differences, socioeconomic status has emerged as the prevailing explanation. The claim is that apparent disparities in health status and quality of care by race and sex actually follow from socioeconomic status differences and the effects those differences have on health care access and quality. The data disparities by race and sex tend to occur because, on average, racial minorities and women earn less and are more likely to be uninsured than are white men. Those effects, according to this explanation, follow from socioeconomic status and not from racial and gender bias. Research produced in the past few years shows that reducing barriers to health care access attributable to low socioeconomic status will reduce much, but not all health disparities. INST. OF MED., UNEQUAL TREATMENT: CONFRONTING RACIAL AND ETHNIC DISPARITIES IN HEALTH CARE 5 (Brian D. Smedley et al. eds., 2003), available at http://www.nap.edu/openbook/ 030908265X/html [hereinafter UNEQUAL TREATMENT]; David R. Williams, Race, Health, and Health Care, 48 ST. LOUIS. U. L.J. 13, 21-26 (2003); see also Ichiro Kawachi, Norman Daniels & Dean E. Robinson, Health Disparities by Race and Class: Why Both Matter, 24 HEALTH AFF. 343, 347 (2005) ("Treating race as a codeterminant of health disparities along with class still leaves open the possibility that race independently influences health through pathways such as personal experiences of discrimination or cultural differences in lifestyles."). In

speaking, the 1990s focus on race, in often decontextualized analyses, allowed race to be defined as if it exists separately and apart from racism. The risk of analyzing race de-linked from racism is that the resulting policy agenda will not address racism. <sup>64</sup>

One risk of analyzing race de-linked from patriarchy is that a race-only focus suggests that the explanations might be simple, if not singular. A multi-axis approach to disparities that includes gender requires, from the outset, attention to the complex interaction between biology and its political representations in health and health care. A lasting accomplishment of the women's health movement has been highlighting the effects of gender, as well as biological sex, on women's health. While biological essentialism still tends to pervade the dominant understanding of women's health, women's health research now includes inquiry into the role of both biological sex and the social construction of gender in health care access, quality of care, and health status. <sup>65</sup> In a multi-axis analysis of disparities, inquiry into the role of

addition, much of the analysis of socioeconomic status ignores the interlocking nature of wealth and race, including the fact that racism limits access to employment, affects insurability, and the ability to accumulate wealth. See Melvin L. Oliver & Thomas M. Shapiro, BLACK WEALTH/WHITE WEALTH (2001); see also INST. OF MED., GUIDANCE FOR THE NATIONAL HEALTHCARE DISPARITIES REPORT 3 (Elaine K. Swift ed., 2002) ("Socioeconomic status is mainly measured using income and education. However, both have different meanings for different racial, ethnic, and other populations, and their use can be problematic when this variation is not taken into account.").

The personal responsibility explanation attributes health or ill-health to an individual's or group's choices about diet, exercise, healthcare seeking or avoidance behavior, etc. Hypothesizing that personal responsibility is a primary contributing factor to health status can deflect attention from institutional barriers to access, quality of care issues, and factors located in larger social structures, such as residential segregation. When used to explain why a racialized group is less healthy than other groups, "personal responsibility" merges into racial stereotypes about that group.

<sup>64</sup> See John O. Calmore, Exploring Michael Omi's "Messy" Real World of Race: An Essay for "Naked People Longing to Swim Free," 15 LAW & INEQ. 25, 28 (1997).

65 See, e.g., Jennifer R. Fishman et al., The Use of "Sex" and "Gender" to Define and Characterize Meaningful Differences Between Men and Women, in AGENDA FOR RESEARCH ON WOMEN'S HEALTH IN THE 21ST CENTURY: A REPORT OF THE TASK FORCE ON THE NIH WOMEN'S HEALTH RESEARCH AGENDA FOR THE 21ST CENTURY 15-19 (1999), available at http://orwh.od.nih.gov/research/resagenda.html (recognizing distinction between sex and gender and identifies research on both aspects of women's health as priority); see also U.S. NAT'L INST. OF HEALTH, OFF. OF RES. ON WOMEN'S HEALTH, FY 2005 NIH RESEARCH PRIORITIES FOR WOMEN'S HEALTH 1, available at http://66.102.7.104/search?q=cache: cr3IOUkD1kEJ:orwh.od.nih.gov/research/FY05ResearchPriorities.pdf (last visited Feb. 1, 2006) (listing sex/gender determinants as one four overarching themes that are important for addressing research on women's health). But see Viviana R. Simon et al., Nat'l Inst. OF HEALTH: Intramural and Extramural Support for Research on Sex Differences, 2000-2003, at 3 (2005) ("The terms 'sex' and 'gender' are often used interchangeably in the

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gender should create space to inquire about the role of racism. In other words, the gender inquiry could be used to leverage the re-linking of race and racism.

# D. The Hope for Convergence

In 2000, the Clinton administration published *Healthy People* 2010<sup>66</sup> and seemingly moved away from the single-axis approach to health disparities and toward a multi-axis approach. *Healthy People* 2010 presented the administration's ambitious public health plan for the first decade of the twenty-first century. This plan used the disparities framework, but stated that "[t]he second goal of *Healthy People* 2010 is to eliminate health disparities among segments of the population, including differences that occur by gender, race or ethnicity, education or income, disability, geographic location, or sexual orientation." In other words, *Healthy People* 2010 seemed to adopt a multi-axis approach that held some promise to reveal the health needs of those who do not live wholly in the categories of race or ethnicity.

The greatest hope has been that the disparities approach would provide room to explore the interaction of various factors, including the ways that multiple linkages of socially constructed identity and status allocate risk. *Healthy People 2010*, in particular, seemed to offer this hope. In more concrete terms, the hope was that the OMH and the ORWH would coordinate their efforts and place the health needs of women of color on the federal health policy agenda. Federal efforts to address racial and gender disparities did seem poised to converge. On March 9, 1994, for example, the NIH published guidelines in the Federal Register on the inclusion of women and minorities in research involving human subjects. The study design of the Women's Health Initiative designated certain centers to recruit women of color for participation. In her 1994 book, Sue V. Rosser stated: "Perhaps this double focus will bring minority women's health concerns to the forefront of the agenda for the first time. It would be tragic if instead women of color became

literature and in grant proposal applications . . . . ").

<sup>69</sup> NIH Guidelines on the Inclusion of Women and Minorities as Subjects in Clinical Research, 59 Fed. Reg. 14,508 (March 28, 1994).

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<sup>&</sup>lt;sup>66</sup> HEALTHY PEOPLE 2010, supra note 1.

<sup>67</sup> Id. at 11.

<sup>&</sup>lt;sup>68</sup> Id.

<sup>&</sup>lt;sup>70</sup> See Bayne-Smith, supra note 51, at 2-3.

the focus of neither office, permitting their health concerns to again slip through the cracks of the research agenda."<sup>71</sup> At the least, it seemed possible that the health needs of women of color, previously omitted from efforts to counter racism and from patriarchy in health care, might actually emerge as a federal policy concern.

#### E. Mixed Results

The results, so far, have not wholly fulfilled either the hopes or fears about addressing health needs particular to women of color. The OMH and the ORWH have each proliferated, in a sense. In addition to those two offices, several other offices of minority and women's health exist within the federal health agency system. The proliferation of offices seems to reflect an effort to address minority health and women's health issues systemically, rather than as a set of discrete and separable issues. NIH and to some extent, FDA data collection efforts have proceeded. The various offices of minority health and women's health report health data by race and sex, thus making women of color statistically present. Various health agencies under the Department of Health and Human Services have policies and programs to increase the participation of women and racial minorities in medicine and biomedical research. If effective, these policies and programs may increase diversity in health care and research, and some of those included may be women of color.

On the other hand, none of these efforts necessarily requires attention to health disparities particular to women of color. Women of color remain only as subcategories of "race" and "sex" in many of these efforts. For example, the Health and Human Services Office of Minority

<sup>&</sup>lt;sup>71</sup> ROSSER, supra note 51, at 86.

The list now includes the Office of Research on Women's Health, National Institutes of Health (http://orwh.od.nih.gov); Office of Women's Health, U.S. Food and Drug Administration (http://www.fda.gov/womens); Office of Women's Health, National Cancer Institute, National Institutes of Health (http://women.cancer.gov); Office on Women's Health, U.S. Department of Health and Human Services (http://www.4woman.gov/owh); Office of Women's Health, Centers for Disease Control and Prevention (http://www.cdc.gov/od/spotlight/nwhw/default.htm); Office of Minority and Women's Health, National Center for Infectious Diseases, Centers for Disease Control and Prevention (http://www.cdc.gov/ncidod/omwh); Office of Minority Health, Centers for Disease Control and Prevention (http://www.cdc.gov/omh/default.htm); National Center on Minority Health and Health Disparities, National Institutes of Health (http://ncmhd.nih.gov/).

<sup>&</sup>lt;sup>73</sup> See supra note 53.

<sup>&</sup>lt;sup>74</sup> For a more extensive discussion of the widely varying definitions of "disparities" see Moy, Dayton & Clancy, *supra* note 50, at 377.

Health typically reports data by race; that data is then categorized by sex. Even the Centers for Disease Control's Office of Minority and Women's Health distinguishes first between "minority" and "women" and then by "sex" and "race," respectively. In federal health policy, women of color are subcategories. The fact that African American, American Indian, Asian American, Latina, and Hawaiian and other Pacific Islander women experience greater or lesser morbidity and mortality rates for some diseases than other race/gender groups often remains unexamined data.

Other initiatives reflect the same pattern. For example, the ORWH funds research. The 2004 list of funded projects includes research that explicitly focuses on Mexican American women; African American women; Native Americans who are lesbian, gay, bisexual, and transsexual; rural women; elderly women; and adolescents; and research on women's health in minority institutions. In these projects, women of color emerge from statistical subcategory status.<sup>75</sup> Some of these studies aim to explore not only health status, but also access and quality of care issues and do so by taking identity, culture, socioeconomic, and political context into account. These studies are more like to identify and probe how and why racialized patriarchy impacts health. Yet these studies seem to be the exception to the prevailing practice of leaving women of color in the subcategories. Relegating women of color to subcategory status is almost predictable in any context, but the disparities framework may have exacerbated the risk that it would happen in federal health research. The disparities framework of the 1990s was largely twodimensional. It provided for the tracking of race differences and sex differences, but not both. It allowed an understanding of difference, in its most reductive sense, to prevail. In doing so, the disparities framework created space for pre-existing priorities, explanations, and failures to pervade the agenda. Federal efforts in the 1990s did make federal health policy more inclusive. But those efforts left untouched most of the issues identified by the women's health movement in the 1970s and the Task Force Reports in 1985 and the ways in which social constructions of women of color mediate health risks particular to members of those groups.

<sup>&</sup>lt;sup>75</sup> U.S. Nat'l Inst. of Health, Off. of Res. on Women's Health, FY 2004 ORWH-Supported Research Initiatives, http://orwh.od.nih.gov/research/FY04Research Summaries.pdf (last visited Jan. 25, 2006).

#### III. THE RETURN TO CIVIL RIGHTS

Federal health policy in the 1990s never ruled out racism as an explanation for health disparities, but neither did it address the role of racism to the extent called for in the 1985 Task Force Reports. In the twenty-first century, however, racism has become a prominent explanation for health disparities. Proposals to reduce racial disparities and the discourse they form signal a return to a civil rights framing of the role of difference in health and health care. Because this framing relinks race and racism, it holds greater promise than the two-dimensional approach to disparities of the 1990s to provide a fuller account of racebased health disparities. But, it retains two features from earlier federal efforts to address the role of sociopolitical difference in health care: structuralism and a single-axis approach. These features could constrain the goals and effects of the disparities efforts, including those of addressing the health needs of women of color.<sup>76</sup>

### A. Unequal Treatment

In 2000, Congress requested the Institute of Medicine "to assess

<sup>&</sup>lt;sup>76</sup> A third factor that may be limiting the effectiveness of the health disparities work is the current administration's reluctance to fully acknowledge the role of racism or even "disparities" in healthcare. The controversy over the publication of the first annual National Healthcare Disparities Report ("NHDR") illustrates this point. In 2003, in response to a Congressional mandate to produce a new annual publication, the Agency for Healthcare Research and Quality ("AHRQ") issued the first annual report. According to the Institute of Medicine, which worked with the AHRQ on the technical aspects of the report, the NHDR "could make a major difference." INST. OF MED., GUIDANCE FOR THE NATIONAL HEALTHCARE DISPARITIES REPORT XI (Elaine K. Swift ed., 2002); U.S. DEP'T OF HEALTH AND HUMAN SERVS., PUB. HEALTH SERV., AGENCY FOR HEALTHCARE RESEARCH AND QUALITY FACT SHEET: NATIONAL HEALTHCARE DISPARITIES REPORT — UPDATE ON CURRENT STATUS (2002). Yet, the events preceding the release of the first NHDR seemed to undercut that potential. In July 2003, the director of the AHRQ sent the report to the Department of Health and Human Services for review. Between that time and the report's December 23 release, staff members revised the report. The revised version watered down the significance of health care disparities. In response to the public outcry, Tommy Thompson, then-Secretary of Health and Human Services, agreed to release the original version of the NHDR. The fact that the revisions occurred and the content of the revisions suggest, perhaps not surprisingly, that the current administration may be less likely than its predecessor to push for federal health policy that takes aim at the role of racism in creating disparate health status and health care. On the other hand, the fact that the revisions yielded to criticism that was quickly organized, high-level, and pointed indicates that the vigor of the public discourse on "disparities" and unequal treatment may be sufficient to maintain its place on the national health policy agenda, regardless of the administration's support.

differences in the kinds and quality of health care received by U.S. racial and ethnic minorities and nonminorities." In 2002, the Institute of Medicine ("IOM") published the resulting report, *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*. The report's first sentence makes its key point: "Racial and ethnic minorities tend to receive a lower quality of health care than nonwhites, even when access-related factors, such as patients' insurance status and income, are controlled." So while the report confirmed that low socioeconomic status substantially impairs access to health care, it unequivocally concluded that racism also significantly impairs the quality of care that persons of color receive. *Unequal Treatment* expressly defined "health care disparities" as "racial or ethnic differences in the quality of health care that are not due to access-related factors or clinical needs, preferences, and appropriateness of intervention" and in doing so, helped place health care disparities on the civil rights agenda.

The report has generated an unprecedented level of government attention to the role of racism in health care and its effects on health status. Many community leaders, public health advocates, providers, social scientists, public interest lawyers, medical educators, and others have long known that the health care system reproduces political inequalities in ways that impair patient care. Many have long worked to improve both access and quality of care for those whose marginalized political status affects health care. Yet, the key point of *Unequal Treatment* — racial inequality in health care — surprised many health policymakers, as well as much of the general public and mainstream media. But the status affects health care in the surprised many health policymakers, as well as much of the general public and mainstream media. But the surprised many health policymakers, as well as much of the general public and mainstream media.

To a large extent, twenty-first century disparities work acknowledges the systemic nature of racism in health care. *Unequal Treatment* acknowledged the deep and complicated nature of the problem: "The sources of these disparities are complex, are rooted in historic and

<sup>&</sup>lt;sup>77</sup> UNEQUAL TREATMENT, *supra* note 63, at 3.

<sup>&</sup>lt;sup>78</sup> *Id.* at 1.

<sup>&</sup>lt;sup>79</sup> *Id.* at 3-4.

<sup>&</sup>lt;sup>80</sup> For a brief account of work done by the NAACP Legal Defense & Education Fund, the National Health Law Program, the Mental Health Law Project, and the Puerto Rican Legal Defense and Educational Fund, see Engelman Lado, *supra* note 25.

<sup>&</sup>lt;sup>81</sup> See, e.g., UNEQUAL TREATMENT, supra note 63, at 2 ("According to two recent polls a significant majority of American believe that blacks like [Robert] Tools [the first surviving recipient of an implantable artificial heart] receive the same quality of healthcare as whites."); Williams, supra note 63, at 13 (citing 1999 national survey that "found that most Americans were unaware that racial disparities in health existed").

contemporary inequities, and involve many participants at several levels, including health systems, their administrative and bureaucratic utilization managers, health care professionals, processes, patients."82 The report calls for a "comprehensive, multi-level strategy."83 Unequal Treatment did not eliminate biological race, socioeconomic status, or personal responsibility as explanations for health disparities. It did, however, unequivocally add racism to the list of significant contributing factors. The addition of racism to the list has redefined health disparities and expanded the disparities framework. It has called attention to earlier research that examined the role of racism in health care and has prompted new efforts to determine how racism intervenes in health care access, quality of care, and health status. The emerging analysis is exciting and useful, but it relies heavily on the structuralist assumption that the problem of racism can be located within a discrete institutional arrangement — the health care system and its standards, norms, and practices. In addition, single-axis approach that has prevailed since the 1940s still dominates the disparities work.

#### B. Health Disparities in a Structuralist World

Most of the proposals emerging from the most recent phase of health disparities work aim primarily at structural change because they assume that racism is expressed and perpetuated in the ways our institutions operate. For example, the proposed interventions include reinvigorating affirmative action programs in the health professions, fostering patient education and empowerment, providing cross-cultural education for health professionals (including nonprovider professionals), bolstering Title VI enforcement, ensuring the same level of care and stability in patient-provider relationships, ensuring the same level of managed care

<sup>&</sup>lt;sup>82</sup> UNEQUAL TREATMENT, *supra* note 63, at 1.

Much of the ensuing research and policy work takes up this broad challenge of addressing the role of institutionalized racism in health care. Some have taken the work further. Scholars such as sociologists David Williams and Chiquita Collins have shown that the root causes lie outside of the health care system. These studies suggest that nothing less than substantive social transformation will effect the elimination of health care inequities. David R. Williams & Chiquita Collins, *Racial Residential Segregation: A Fundamental Cause of Racial Disparities in Health*, 116 Pub. Health Rep. 404-07, 411, 413 (Sept./Oct. 2001).

<sup>&</sup>lt;sup>84</sup> See, e.g., UNEQUAL TREATMENT, supra note 63, at 186.

<sup>85</sup> *Id.* at 196-98.

<sup>86</sup> Id. at 199-214.

<sup>87</sup> Id. at 188.

protections to patients enrolled in publicly funded health plans as those in privately funded plans receive, <sup>88</sup> and gathering additional disparities data. <sup>89</sup> A recent issue of *Health Affairs*, dedicated to "Racial and Ethnic Disparities," includes proposals to use "Medicare as a Catalyst for Reducing Health Disparities," "Creating a State Minority Health Policy Report Card," expanding health insurance coverage, <sup>93</sup> and improving the use of race/ethnicity data by health care organizations. <sup>94</sup> These examples do not fully describe the breadth of the work being proposed and implemented to reduce racial and ethnic disparities in health care, but they do represent the dominant approach to disparities work.

The dominant approach assumes that the reasons for health care disparities are located in health care's institutional arrangements, standards, and practices. From a structuralist standpoint, implementing affirmative action and cross-cultural training would not only eliminate racist and mono-cultural institutional practices that impair patient care, but also eliminate racism in health care. In fact, affirmative action could create more opportunity for racial concordance between physician and patient, which correlates with participatory decision-making. Cross-cultural training enhances patient compliance with therapeutic protocols. In addition, advocates hope that these remedies will change the people who work in the institutions — health professionals will internalize the lessons of affirmative action and cross-cultural training. Some of that may happen.

While the short-term hopes for these remedies are well-founded, the greater ambition of using structural change to address racist ideology

<sup>88</sup> Id. at 182-88.

<sup>89</sup> Id. at 215-34.

<sup>90 24</sup> HEALTH AFF. 312-582 (2005).

<sup>&</sup>lt;sup>91</sup> June Eichnor & Bruce C. Vladeck, Medicare as a Catalyst for Reducing Health Disparities, 24 HEALTH AFF. 365, 365 (2005).

<sup>&</sup>lt;sup>92</sup> Trivedi et al., supra note 4, at 388.

<sup>&</sup>lt;sup>93</sup> Lillie-Blanton & Hoffman, supra note 4, at 407.

<sup>94</sup> Nerenz, *supra* note 4, at 410, 415.

<sup>&</sup>lt;sup>95</sup> See Lisa Cooper-Patrick et al., Race, Gender, and Partnership in the Patient-Physician Relationship, 282 JAMA 583, 586-89 (1999).

<sup>&</sup>lt;sup>96</sup> See Nieli Langer, Culturally Competent Professionals in Therapeutic Alliances Enhance Patient Compliance, 10 J. HEALTH CARE FOR POOR & UNDERSERVED 19, 24 (1999); see also Glenn Flores, Culture and the Patient-Physician Relationship: Achieving Cultural Competency in Health Care, 136 J. PEDIATRICS 14, 15 (2000); Steven Woloshin et al., Language Barriers in Medicine in the United States, 273 JAMA 724, 725 (1995).

<sup>&</sup>lt;sup>97</sup> See, e.g., Carol Vlassoff & Claudia Garcia Moreno, Placing Gender at the Center of Health Programming: Challenges and Limitations, 54 SOC. SCI. & MED. 1713, 1719 (2002).

has proven overstated. Structuralism lends itself to identifying necessary changes in tangible practices and articulated standards. It does not, however, respond to the resilience and adaptability of dominant ideology. Racism and patriarchy persist even as their forms change. As new practices and standards emerge, ideology flows in and provides the content. For example, the emergence of biological race in the disparities discourse at this time may not be coincidence, but may instead be a timely adaptive response to the reintroduction of civil rights in health care. The legitimacy of biological race as an explanation for disparities may depend more on its ability to contain the antiracist discourse rather than on scientific evidence.

Structuralism may also be inhibiting researchers and policy analysts from addressing health care issues particular to women of color. Traditionally, structuralism's strength has been its ability to acknowledge and explain difference, but not naturalize it. 98 In the health care setting, considering the "natural" or biological is necessary in evaluating health status and health care. Yet, while women's biological capacity to bear children might affect women's health, what we make of it — gender — might also affect women's health care and, hence, their health. Despite the best efforts of women's health advocates, the status of science as a neutral body of knowledge, produced by rigorous, nonpolitical methods still tends to run interference for the conflation of the natural and the socially-constructed in health. The resurrection of biological race as an explanation for health disparities particularly heightens the risk of that conflation for women of color. The heightened risk arises because the distinction between sex and gender in health cases depends on a construction of gender that is based on the experience of white women. As a result, when the health status of women of color is worse that that of white women, lifestyle or biological race surface as explanations rather than particularized forms of subordination.

#### C. In the Shadows of Race

Unequal Treatment not only validated discrimination as a significant explanation for health care disparities, but also seems to have refocused the disparities discourse on race and racism. This focus may overshadow other contributors to health disparities. In fact, that may

<sup>&</sup>lt;sup>98</sup> See Martha Chamallas, Structuralist and Cultural Domination Theories Meet Title VII: Some Contemporary Influences, 92 MICH. L. REV. 2370, 2382 (1994).

have happened already. Kawachi et al. observed that, "[d]espite the inclusive vision of *Healthy People 2010*, one interpretation of the legislative and policy actions that followed in its wake is that they have primarily concentrated on reducing racial disparities." As a result, the federal commitment "to eliminate health disparities among segments of the population, including differences that occur by gender . . . education or income, disability, geographic location, or sexual orientation" may move down or off the federal health policy agenda. <sup>101</sup>

Black feminists, critical race feminists, and others have established that efforts to eliminate racism without specific attention to the experience of women of color do not fully address sociopolitically allocated risks to women of color. In some instances, race-only efforts exacerbate the risks. Patricia Hill Collins has shown that race and gender are constructed differently and that the experiences and identities formed at the matrices of these constructs are unique and nonderivative. 102 Race, then, is an inaccurate proxy for gender, even when applied to women of color. 103 For example, the 1999 Schulman study made headlines when it clearly demonstrated that racial and gender bias affect physician decisionmaking about treatment for chest pain. 104 The study showed that physicians would have provided different medical treatment to white men, white women, Black men, and Black women who were similarly situated in terms of socioeconomic status and health status. Physician decision-making showed the highest disregard for Black women, even compared with white women and Black men. An antiracist intervention

<sup>99</sup> Kawachi et al., supra note 63, at 347.

<sup>&</sup>lt;sup>100</sup> HEALTHY PEOPLE 2010, supra note 1, at 11.

<sup>&</sup>lt;sup>101</sup> Kawachi et al., *supra* note 63, at 347; *see*, *e.g.*, Healthcare Equality and Accountability Act, H.R. 3561, 109th Cong. (1st Sess. 2005) (creating wide-ranging bill "to improve the health of minority individuals" that includes provision for research on few specific health conditions that affect women of color and for services for low-income pregnant women, but overwhelmingly provides for "minority health" without attention to how racialized patriarchy affects women and men.).

 $<sup>^{\</sup>tiny 102}$  Patricia Hill Collins, Black Feminist Thought 27-28 (1990).

<sup>&</sup>lt;sup>103</sup> I do not think a race-only approach to health disparities is or would be based on the claim that race is a proxy for gender. In biomedical research, the categories are considered as too different to operate as stand-ins for each other. *See* Nancy Krieger & Elizabeth Fee, *The Biopolitics of Sex/Gender and Race/Ethnicity, in* MAN-MADE MEDICINE, *supra* note 29, at 21. I am, instead, addressing the more likely assumption that a race-only approach might incidentally and substantially address the needs of women of color. This assumption, I believe, makes sense from an additive approach to race-gender intersection issues. I do not embrace that approach.

<sup>&</sup>lt;sup>104</sup> Kevin A. Schulman et al., *The Effect of Race and Sex on Physicians' Recommendations for Cardiac Catheterization*, 340 New Eng. J. Med. 618, 618 (1999).

that failed to take that phenomenon into account would fall short of addressing the health needs of Black women.

The most obvious result of race-only efforts would be the disappearance of women of color from the federal health agenda. Without an explicit gender analysis, the androcentrism that has pervaded federal health and research programs would characterize its antiracism efforts as well. This would further reduce the potential for convergence between race-based disparities efforts and women's health programs. Women of color would then remain statistical categories in most federal health initiatives.

Two facile equations could mask the exclusion. The first is that between race and gender as applied to women of color. In other words, using race as a proxy for the health risks that women of color experience would not only cause but also mask their exclusion from the health agenda. The second arises from the fact that we take statistical categories so seriously that conflation between the statistical presence of women of color and substantive inclusion may not be noticed. Either equation would ensure that risks and issues significant to women of color would remain politically marginalized.

A more subtle effect of using a race-only approach to health disparities is that acknowledging racism without addressing the interlocking aspects of patriarchy can reinforce the naturalization of gender. Biological essentialism is more central to constructions of gender than it is to racial construction. As noted above, physical differences between biological females and biological males seem to give scientific credence to socially constructed gender essentialism. The centrality of biology to both sex and gender has made the feedback loop between them more difficult to challenge than biological race. <sup>107</sup>

health dollars and the research agenda are still disproportionately allocated to health risks particular to men. See, e.g., SIMON ET AL., supra note 65 (reviewing NIH grants by subject matter, and concluding that grants awarded for studying sex differences constitute very small percentage of grants awarded); Barbara A. Goff et al., Comparison of 1997 Medicare Relative Value Units for Gender-Specific Procedures: Is Adam Still Worth More Than Eve?, 66 GYNECOLOGIC ONCOLOGY 313, 313 (1997). Kimberlé Crenshaw's theory of intersectionality predicts this outcome. In antidiscrimination law, Professor Crenshaw traced the now-familiar pattern — the most privileged within a minority group are the most likely to benefit from antidiscrimination interventions. Kimberlé Crenshaw, Demarginalizing the Intersection of Race and Sex: A Black Feminist Critique of Antidiscrimination Doctrine, Feminist Theory and Antiracist Policies, 1989 U. CHI. LEGAL F. 139, 152.

<sup>&</sup>lt;sup>106</sup> COLLINS, supra note 102, at 27.

<sup>107</sup> The effectiveness of civil rights claims in the 1960s hinged, in part, on undercutting

As a result, a race-only approach to health disparities will leave intact the ways in which gender allocates health risks among men and women. The apparently biological basis for gender would make disproportionate allocations of risk to women or men seem unavoidable. The naturalization of gender-based misallocations of health risk would then be more likely to remain unchallenged.

# IV. THE ROLE OF CRITICAL THEORY IN DEVELOPING HEALTH POLICY FOR WOMEN OF COLOR

Using structuralism's strengths paired with critical cultural inquiry can produce insights, as well as strategies for expanding federal health policy beyond a race-only approach. A critical cultural analysis of access barriers identified by structuralist inquiry can help hone proposals for legal intervention. Critical analysis can also help identify the subtle ways that dominant ideology resurfaces again and again. These points may be useful for clarifying political goals and strategies.

## A. A Structuralist Inquiry

Structuralism, as noted, locates discrimination in the structures, standards, and practices of institutions. In the health care setting, the structuralist inquiry delves into health care financing, as well as the institutions that provide health care. One of structuralism's strengths is that it reveals openings for legal intervention. Regulating institutions is, after all, a large part of what law does. The key step is to identify the ways in which the organization, standards, and practices of health care interfere with the health care of women of color more substantially or differently than with the health of other groups.

A cursory structuralist search for institutional portals for bias against

biological racism. We remember Reverend Martin Luther King, Jr.'s hope that "my four little children will one day live in a nation where they will not be judged by the color of their skin but by the content of their character," because it so eloquently captured the movement's central moral claim. See Martin Luther King, Jr., Address at the March on Washington for Jobs and Freedom: I Have a Dream (Aug. 28, 1963), available at http://www.stanford.edu/group/King/publications/speeches/address\_at\_march\_on\_wa shington.pdf. It refuted the notion of inherent inferiority. While subsequent political shifts to formal notions of equality, deeper understandings of culture-race arising from identity politics and shallower understandings that conflate race and culture have not fully sustained antiracist work; they have, until recently, helped hold biological racism at bay. See TROY DUSTER, BACKDOOR TO EUGENICS 146-62 (2d ed. 2003). They have not, however, prevented the persistence of gender essentialism.

bio litt women of color might reveal several important insights. Structuralism is particularly effective at identifying access barriers. A structuralist analysis yields the observations that health care's costs pose a barrier to many, but the risk of being underinsured is higher for some women of color than for men or white women. For example, a 1996 assessment of health care access for older women of color stated:

Persons of color are the least likely to have private health insurance and are twice as likely to have only Medicare without supplemental insurance . . . . Underinsurance, for poor and low-income elders, particularly the oldest old and women of color, continues to be a key factor in the accessibility and use of health care services. <sup>108</sup>

Other access barriers identified by attention to the effects of institutional practices include culture and language. Women in some cultural minority communities might find it difficult, if not impossible, to communicate freely with or undergo a physical examination by a man. This could cause unwillingness to seek health care or inability to obtain adequate health care from male providers. Monolingual health care may impact women with limited English proficiency because women often act as the brokers for family health care. The lack of language assistance services may then have three effects. It may prevent a woman from obtaining care or obtaining adequate care. It may impair her capacity to procure care for her family and therefore prevent them from obtaining health care. It may also impair her role within the family. In fact, in the absence of language assistant services, the responsibility often shifts to children or other family members of the

Donna L. Yee & John A. Capitman, *Health Care Access, Health Promotion, and Older Women of Color*, 7 J. Health Care for Poor & Underserved 252, 255 (1996); *see also* Michelle M. Doty et al., *Seeing Red: Americans Driven into Debt by Medical Bills: Results from a National Survey, in* Commonwealth Fund pub. #837 (2005) (finding that annually one of three adults have problems paying medical bills and that women, African American adults, and adults with health problems have the highest rates of problems). The study did not correlate any of those data groups. *Id*.

<sup>&</sup>lt;sup>109</sup> See Lisa C. Ikemoto, Racial Disparities in Health Care and Cultural Competency, 48 St. LOUIS U. L.J. 75, 86-87 (2003).

 $<sup>^{\</sup>mbox{\tiny 110}}$  Julie L. Gerberding, Women and Infectious Disease, 10 Emerging Infectious Diseases 1965, 1966 (2004).

<sup>&</sup>lt;sup>111</sup> Providers who think they have sufficient language proficiency often misunderstand patients or make incorrect, confusing, or insulting replies. Linda Haffner, *Translation Is Not Enough: Interpreting in a Medical Setting*, 157 W.J. MED. 255, 258 (1992). Some of the errors can affect diagnosis and treatment. OFF. OF MINORITY HEALTH, U.S. DEP'T OF HEALTH AND HUMAN SERVS., NATIONAL STANDARD FOR CULTURALLY AND LINGUISTICALLY APPROPRIATE SERVICES IN HEALTH CARE: FINAL REPORT 76 (2001).

person whose primary language is not English.

Another of structuralism's strengths is its ability to identify the ways that institutional standards and practices provide cover for stereotyping. For example, research shows that the institutional brokers of health care access often exercise their discretion in discriminatory ways. <sup>112</sup> Negative stereotypes about Black women, Latinas, and Asian women abound and provide unofficial reasons for deciding against aggressive treatment for coronary heart disease <sup>113</sup> or for deciding not to advocate for a nonstandard therapy with a utilization manager. <sup>114</sup> The resulting health care is lower in quality than that given to others.

Structuralist analysis also reveals that "[t]he health system, and the medical hierarchy within it, replicate many of society's power relationships: between doctors and nurses, doctors and clients and nurses and clients." In other words, most providers are women, but most physicians are men, and women of color tend to occupy the lower rungs of the hierarchy. The replication of race, gender, and class hierarchies may reinforce or seem to "prove" stereotypes that, in turn, intervene in quality of care. Placement at the bottom of the hierarchy carries increased risk that health care will be impaired. Women of color, then, probably bear the greatest risk.

A structuralist inquiry would probably produce a list of institutional changes and legal interventions substantially similar to those already proposed. Expanding health insurance coverage, providing crosscultural training, expanding language assistance services, enforcing Title VI, and implementing or reinvigorating affirmative action would appear

<sup>&</sup>lt;sup>112</sup> UNEQUAL TREATMENT, *supra* note 63, at 151-53; M. Gregg Bloche, *Race and Discretion in American Medicine*, 1 Yale J. Health Poly L. & Ethics 95, 99-106 (2001); Ikemoto, *supra* note 109, at 80-83.

<sup>&</sup>lt;sup>113</sup> See Schulman et al., supra note 104, at 624-25.

<sup>&</sup>lt;sup>114</sup> Unequal Treatment, supra note 63, at 151.

<sup>&</sup>lt;sup>115</sup> Vlassoff & Moreno, supra note 97, at 1718.

<sup>&</sup>lt;sup>116</sup> See Sue Fisher, In the Patient's Best Interests: Women and the Politics of Medical Decisions 30-31 (1990) [hereinafter Fisher, Patient's Best Interests]; Sue Fisher, Nursing Wounds: Nurse Practitioners, Doctors, Women Patients, and the Negotiation of Meaning 202 (1995); Irene H. Butter et al., Gender Hierarchies in the Health Labor Force, in Women's Health, Politics, and Power: Essays on Sex/Gender, Medicine, and Public Health 79 (Elizabeth Fee & Nancy Krieger eds., 1994), Jerry L. Weaver & Sharon D. Garrett, Sexism and Racism in the American Health Industry: A Comparative Analysis, in Women and Health: The Politics of Sex in Medicine, supra note 28, at 79.

 $<sup>^{117}\,</sup>$  See Fisher, Patient's Best Interests, supra note 116, at 150-62; Weaver & Garrett, supra note 116, at 97-101.

on the list. The proposals might call for particular attention to the needs of women of color. Cross-cultural training might include a bit of gender analysis as well as race and culture analysis. The affirmative action goals might explicitly include Latinas, Black women, Native American and Alaskan women, Pacific Islander, and Asian American women. These proposals are worth fighting for. They would result in better health care access and health care quality for women of color. They might not, however, prevent the underlying ideologies from reconstituting into new practices and standards that would, in turn, undermine the gains made.

# B. A Critical Cultural Inquiry

Critical cultural inquiry focuses on cultural formation and the role of ideology in cultural formation and in sustaining existing power Because of its attention to power and to power arrangements. imbalances, John Calmore has characterized cultural studies as oppositional practice. 118 That characterization suggests that the analytical process itself can, in certain circumstances, intervene in cultural formation, 119 show the possibility for intervention by revealing the artifice and politics in culture, 120 or point toward effective means of rejecting the dominant ideology. Cultural inquiry's exposure of the malleability of culture and the plasticity of ideology also makes it easier to consider multiple differences without locking them into a particular form or meaning and without treating different social constructions as simple variations on a theme. Cultural inquiry, then, can more fully account for how racialized patriarchy operates in health care.

At one level, critical inquiry can provide a more nuanced account of a problem identified by structuralist inquiry. A Korean-speaking woman with a gynecology appointment at a county hospital might face at least two access barriers — a lack of language assistance services and a lack of cultural competency. A structuralist account of the need to remedy those problems would focus on the woman patient's lack of English proficiency and her cultural beliefs. A structuralist evaluation of the

<sup>&</sup>lt;sup>118</sup> John O. Calmore, *The Law and Culture-Shift: Race and the Warren Court Legacy*, 59 WASH. & LEE L. REV. 1095, 1104 (2002).

<sup>&</sup>lt;sup>119</sup> *Id.* at 1108-09; see also Thomas B. Stoddard, Bleeding Heart: Reflections on Using the Law to Make Social Change, 72 N.Y.U. L. REV. 967, 977-78 (1997) (addressing the potential for law to effect "culture-shifting" or cultural change).

<sup>&</sup>lt;sup>120</sup> See Patricia Williams, A Brief Comment, with Footnotes, on the Civil Rights Chronicles, 3 HARV. BLACKLETTER L.J. 79, 80-81 n.3 (1986).

hospital staff's solution — to ask a sixteen-year-old boy in the waiting room, a complete stranger, to interpret for the woman and her doctor — might point to a Korean belief that gynecological matters are extremely private and that the age and gender differences between the woman and boy would make communication nearly impossible. On the other hand, a critical inquiry would also examine the institution's culture, gender, race, and age norms and how cultural domination resulted in asking a sixteen-year-old boy in the waiting room to interpret. The resulting understanding might lead to a demand not only for cultural competency training, but also for a type of cultural competency training that produces awareness of the interactions between dominant and minority cultures and the effects on both institutional actors and patients.

A second level inquiry might begin by examining the ideological content of health care's most basic concepts. Consider "health" and "women's health." The efforts of women's health advocates have partly defined "women's health" as a category made necessary by the exclusion from "health" of issues specific to women. "Women's health," in that sense, is a category established as an oppositional practice. "women's health" also evidences dominant culture's hand, as well. Gender essentialism has effectively constrained "women's health" to reproductive and sexual health or women's capacity to engage in sex, become pregnant, gestate, and give birth. Hence, the definition of "women's health" contains the oversignification of reproductive biology that operates in other gendered constructions. The disparities efforts are expanding the understanding of "women's health" by producing data on coronary heart disease, stroke incidence, and lung cancer mortality. In a sense, the disparities data is making the entire female body visible in and relevant to health policy. Even while the disparities data is pushing "women's health" beyond reproductive health, the use of data without accompanying critical inquiry may be creating space for the same old explanations — socioeconomic status, biology, or lifestyle — to flow into the gaps.

Another level of inquiry might, therefore, take aim at the formation and use of the data. The problem with relying primarily, if not solely, on data derives from the effect of the data categories on discourse. The categories, by virtue of their mere existence and their status as

<sup>&</sup>lt;sup>121</sup> See Ikemoto, supra note 109, at 87.

<sup>&</sup>lt;sup>122</sup> See id.

government designations, tend to become fixed. In addition, they reify themselves as empirical fact. Michael Omi has written about the phenomenon even among sociologists: "Much of sociological research, though firmly committed to a social as opposed to biological interpretation of race, nevertheless slips into a kind of objectivism about racial identity and racial meaning." Subcategories, especially those filled only with statistical data, data about health and science-based knowledge, must also be vulnerable to this phenomenon.

The absence of explanatory content in the subcategories, along with a lack of analytical focus on the statistical overlaps leads to the risk that causation will simply be imported wholesale from other sources. There are three likely sources. They come, most recently, from the 1990s shift to disparities. As discussed above, the dominant explanations for health disparities in the 1990s were biology, socioeconomic status, and lifestyle. Each of these explanations seem politically neutral. In fact, each explanation taps into pre-existing narratives that blame women of color for various social problems — over-fertility, the black/immigrant underclass, and culture of poverty. In doing so, these explanations actually import ideology, but their clothing in apparently empirical categories makes them seem like fact.

Critical cultural inquiry gets to what structuralism does not. While structuralism's insights often translate readily into proposals for legal intervention, cultural inquiry reveals what law does not easily reach. It also reveals that law is as much a part of the problem as it is a blunt tool for fixing the problem. This inquiry into the federal government's efforts to address the role of difference in health and health care is also about the law's role in defining difference in ways that have continuously placed the health needs of women of color in the shadows. Changing the law, therefore, might help place women of color on the national health agenda. But political pressure is also needed to contain the ideological forces that have so successfully reasserted themselves in the past.

History shows that health policy and law are amenable to critical inquiry. Civil rights advocates and women's health advocates have changed both federal health policy and the definition of health. The shift to disparities in the 1990s would never have happened but for the political pressure they have brought to bear over the years. In addition, the use of contextualized critical analysis of the disparities data gave *Unequal Treatment* its key insight — that racism contributes significantly

<sup>&</sup>lt;sup>123</sup> Omi, *supra* note 50, at 21.

to health disparities — and gave that insight force. Critical inquiry changed the disparities discourse. It can happen again.

#### **CONCLUSION**

Health disparities work is at the research and development stage. Unequal Treatment produced a shift in disparities discourse toward the role of racism in health care. No effort to reduce disparities could succeed without the goal of eliminating racist health care. However, the resulting attention to race is, for now, overshadowing the role of other socially constructed contributors to unequal health care, and no effort to reduce disparities can succeed without intervening in the operation of those contributors as well. Neither the disparities research agenda nor the discourse has solidified. The federal government published its ambitious public health agenda, Healthy People 2010, five years ago. The goal of eliminating "health disparities among segments of the population, including differences that occur by gender, race or ethnicity, education to income, geographic location, or sexual orientation," is only five years away. We may not eliminate disparities by 2010, but we can make serious progress if we take seriously the goal of using a multi-axis approach. Using critical cultural inquiry to hone the legal interventions produced by structuralist analysis, stepping up political pressure to eliminate all forms of unequal health care, and questioning the most basic concepts for ideological content can help expand the agenda.