The Health Care Challenge: Acknowledging Disparity, Confronting Discrimination, and Ensuring Equality

Volume I
The Role of Governmental and Private Health Care Programs and Initiatives

A Report of the United States Commission on Civil Rights
September 1999

U.S. Commission on Civil Rights

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- Investigate complaints alleging that citizens are being deprived of their right to vote by reason of their race, color, religion, sex, age, disability, or national origin, or by reason of fraudulent practices;

- Study and collect information relating to discrimination or a denial of equal protection of the laws under the Constitution because of race, color, religion, sex, age, disability, or national origin, or in the administration of justice;

- Appraise Federal laws and policies with respect to discrimination or denial of equal protection of the laws because of race, color, religion, sex, age, disability, or national origin, or in the administration of justice;

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Letter of Transmittal

The President
The President of the Senate
The Speaker of the House of Representatives

Sirs:

Pursuant to Public Law 103-419, the United States Commission on Civil Rights transmits this report, *The Health Care Challenge: Acknowledging Disparity, Confronting Discrimination, and Ensuring Equality*. With this two volume report, the Commission examines the efforts of the U.S. Department of Health and Human Services (HHS) Office for Civil Rights (OCR) in enforcing title VI of the Civil Rights Act of 1964, title IX of the Education Amendments of 1972, the requirements under the Hill-Burton Act of 1946, and the nondiscrimination provisions of the community block grant programs administered by HHS. In particular, the Commission's report focuses on the enforcement of these nondiscrimination laws and their impact on ensuring equal access to quality health care for all Americans, particularly women and members of racial and ethnic minority groups.

Until this year, the Commission had not conducted a comprehensive evaluation of HHS. Examining the issue of health care is critical, particularly from the civil rights perspective, because it has implications for all individuals. Access to health care should be a fundamental right; however, it has not been viewed as such by the Federal Government or the health care industry. The fact that disparities in health status continue to exist despite the political and economic rhetoric surrounding health care is an indication that civil rights enforcement efforts need to be reassessed and more clearly focused.

The first volume of this report, *The Role of Governmental and Private Health Care Programs and Initiatives*, examines the racial, ethnic, and gender disparities in health status, health research, access to health services, and health care financing. The Commission found that despite efforts to eliminate discrimination and improve access to health care for minorities and women, there has been little change in the quality of, or access to, health care for members of these groups. Discrimination in the health care system continues to manifest itself in many ways, including: differential delivery of health care services based on race, ethnicity, and gender; inability to access health care because of lack of financial resources, culturally incompetent providers, language barriers, and the unavailability of services; and exclusion of minority and female populations from health-related research. The result of these forms of discrimination is the perpetuation of striking disparities in health status between minorities and nonminorities, among members of population subgroups, and between men and women. Such discrimination is furthered in part by the failure of appropriate Federal agencies to implement and enforce civil rights laws in the health care context.

If the Nation is to fully eradicate health care disparities, unified efforts of Federal, State, and local governments, as well as private organizations, are needed. Congress and the President must design and implement a plan which ensures that all individuals, regardless of race, ethnicity, gender, or socioeconomic status, have financial access to quality health care. Funds should be allocated for an initiative specifically designed to identify solutions and to close the health care financing gap—the gap between qualifying for existing public assistance programs and being able to afford private health insurance.

However, universal coverage does not necessarily mean that everyone would experience universal access to *quality* health care. Congress, the President, and HHS, with the legislative and financial power to significantly affect all aspects of health care in the United States, must reassess their agenda to include the perspectives of women and people of color and must reevaluate the methodology of health care with these groups in mind. In conjunction with the Office for Civil Rights, the offices of women's and minority health throughout HHS should take a more proactive role in the incorporation of these populations' health issues in HHS. Treated as "peripheral," these offices are forced to operate under the constraints of extremely limited budgets. HHS must recognize the potential impact of these offices and increase funding accordingly.

The Office of the Secretary should direct OCR and the offices of women's and minority health in undertaking several strategies to enhance the consideration afforded women and minorities in health care delivery and research. First, these offices should work in cooperation to ensure that HHS and recipients of HHS funding take sociocultural contexts of individuals' lives into consideration when designing and reviewing health programs. Health professionals must be educated about the severity of racial, ethnic, and gender disparities in access to health care and strategies necessary to eliminate such inequities. Most important, education and training to enhance the provision of culturally effective health care must be integrated into lifelong learning for health care providers.

Another focus of the Office of the Secretary, OCR, and the offices of women's and minority health should be the lack of medical research by and about minorities and women. HHS must take the lead in enforcing the mandated inclusion of females and minorities in health-related research, both as participants in and recipients of Federal funds for research. OCR and the offices of women's and minority health can assist this effort by monitoring progress made by research organizations in including females and minorities in research. Offices of women's and minority health should also encourage HHS researchers and scientists in making efforts to reach underrepresented communities and reevaluating scientific protocol so that it is congruent with the beliefs and practices of those communities. Further, although there have been many important gains made in research on the health of women and people of color, adequate funding is critical to address additional questions, confirm what initial studies have found, and engender understanding of the implications of such research.

Third, the Office of the Secretary should ensure coordination among the offices of women's and minority health, OCR, the HHS operating divisions, and State and local governments, to integrate civil rights objectives into all health care initiatives during initial planning stages, as well as throughout implementation. HHS must take a proactive approach in integrating civil rights concerns into health care rather than attempting to address discrimination after it occurs. OCR and the offices of women's and minority health must remain informed of all departmental activities affecting health care, nationally as well as locally, including those of the operating divisions. In addition they must be aware of initiatives at the State and local levels, coordinating with them whenever possible.

Fourth, for health care programs to be effective in reducing disparities and improving conditions for women and people of color, they must be implemented at the community level, particularly in conjunction with community-based organizations. The ultimate goal should be the inextricable integration of the health of women and people of color into every project, every grant, and every program from the initial stages of development. The offices of women's and minority health should provide leadership in accomplishing this goal.

However, it also is necessary to recognize that new programs and initiatives alone cannot improve the health of the Nation. OCR, as the civil rights enforcement office of the Federal agency responsible for the Nation's health, must be actively involved in eliminat-

ing health care practices that result in unequal access to and receipt of *quality* health care. Failure to do so results in an unstated acceptance of poor or nonexistent health care for minorities and women, and a perpetuation of inequality in the Nation's health care system. Volume II of this report assesses OCR's performance in enforcing civil rights in HHS-funded health care programs.

Respectfully,
For the Commissioners,

Mary Frances Berry
Chairperson

Preface

Introduction

Equal access to quality health care is a crucial issue facing our Nation today. For too long, too many Americans have been denied equal access to quality health care on the basis of race, ethnicity, and gender. Cultural incompetence of health care providers, socioeconomic inequities, disparate impact of facially neutral practices and policies, misunderstanding of civil rights laws, and intentional discrimination contribute to disparities in health status, access to health care services, participation in health research, and receipt of health care financing. Such disparities persist in part because of inadequate enforcement of Federal civil rights laws relating to health care by the U.S. Department of Health and Human Services (HHS). For many years, title VI of the Civil Rights Act of 1964, the community service assurance provisions of the Hill-Burton Act, title IX of the Education Amendments of 1972, and the nondiscrimination provisions of block grant statutes have not been fully enforced and implemented by HHS' Office for Civil Rights (OCR).

Equal access to quality health care is a civil right. Although Congress has enacted civil rights laws designed to address specific rights, such as equal opportunity in employment, education, and housing, it has not given health care the same status. Regardless, unequal access to health care is a nationwide problem that primarily affects women and people of color. The lack of availability and quality of health care, the lack of affordable financing of health care, and the likelihood of minorities and women not being included appropriately in medical research are realities as we approach the 21st century. Despite the many initiatives and programs implemented at the Federal, State, and local levels, the disparities in health care will not be alleviated unless civil rights concerns are integrated into these initiatives and programs.

The Commission's Evaluation of Civil Rights Enforcement at HHS

The Commission's two reports on equal access to health care as a civil right develop complementary themes, with volume I setting the stage for volume II. With these reports, the Commission provides recommendations focusing on eliminating racial, ethnic, and gender disparities in health care and improving HHS' civil rights enforcement activities. These reports clearly demonstrate that OCR has been operating in a vacuum for many years, has not asserted its enforcement authority, and is not necessarily aware of the many initiatives and programs aimed at improving access to health care for women and minorities. Volume I documents the need for more collaboration between OCR and Federal, State, and local agencies; the deficiencies and disparities highlighted in volume I can be significantly reduced through proper civil rights enforcement, as identified in volume II.

This report is the result of months of research and careful assessment of materials gathered from a wide variety of sources. In an effort to conduct balanced research, Commission staff solicited diverse scientific viewpoints by contacting numerous private research and advocacy organizations, including organizations representing alternative viewpoints. Further, in gathering information, a request was sent to more than 150 health care organizations, professional groups, research institutes, and advocacy groups representing a wide range of constituents and from all points on the political spectrum. In addition, medical schools, teaching hospitals, and State health agencies across the country were contacted for input.

Statements in these reports are based on interviews, HHS documents, and research findings. The pertinent health care issues presented have been identified by the Federal Government as well as private health care organizations and researchers. The discussions in both volumes of the report were informed by multiple sources, as is evidenced by the bibliography which includes more than 350 documents, articles, and interviews. Included are HHS docu-

ments, studies and surveys by national organizations, articles in health care research journals, and other research that cites experts in the field.

As the law must comprise the foundation for any enforcement evaluation, the Commission consulted law review articles, as well as statutes, regulations, guidelines, and policy guidance. In addition, to encompass the medical aspects of the issue, the report includes the viewpoints of numerous physicians and medical experts (researchers and practicing physicians) by way of the medical journals, government and private reports, and law review articles. Data cited are from reputable sources such as the American Medical Association, the Association of American Medical Colleges, the National Institutes of Health, the National Center for Health Statistics, and other agencies in the Department of Health and Human Services. The stories told by the majority of these sources reveal the findings presented in this report: that health care disparities continue to exist, and proactive, effectual remedies are imperative.

Health Disparities

Barriers to Access to Health Care

In developing this report, it was discovered that there is no universal agreement on the causes of racial, ethnic, and gender disparities in health status, nor is there only one source of such disparities, but there are a few that have the most direct effect. One obvious determinant of health status is access to health care, including preventive care and necessary treatment. Factors that impede access to care are discussed in detail throughout this report. For example, health care financing, particularly the ability to obtain health insurance, is one of the most prevalent health care concerns of all Americans and presents a particular challenge for minorities and women.[1] Other barriers to access identified in this report include language barriers, cultural misunderstanding on the part of both the provider and the patient, lack of available services in some geographical areas (such as inner cities and rural communities), and lack of transportation to services.

Behavioral Factors and Health

Critics will often cite lifestyle and behavioral habits as defining factors of health status; however, this is a faulty assumption in many instances. While it is true that certain lifestyle behaviors—smoking, alcohol consumption, poor diet, etc.—can be correlated to poor health status, this report demonstrates that these behaviors actually account for only a modest portion of health disparities across age, sex, and race categories.[2] This argument also fails to take into consideration the extent to which personal choice is limited by opportunities, such as low income, the unavailability of nutritious foods, and lack of knowledge about healthy behaviors. When personal responsibility is cited as the sole explanation for poor health, factors that are not entirely within an individual's control can become a source of blame. This is not to suggest that individuals should not take responsibility for their own health, rather it is acknowledged that personal responsibility should become part of the regimen for improving health.[3]

Socioeconomic Status and Poor Health

A major premise of volume I of this report is that the combined variables of race, ethnicity, gender, and socioeconomic status intersect to have an undeniable adverse effect on the ability of many Americans to obtain health care. Certainly, health status is related to poverty; and socioeconomic status and race are intimately linked.[4] As the findings here indicate, overall, minorities have a lower median weekly income and are more likely to be below the poverty line than

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[1] *See* vol. I, chap. 3.

[2] *See* vol. I, chap. 2.

[3] *See* vol. I, chap. 2.

[4] *See* vol. I, chap. 2.

whites.[5] Inequalities in education, income, and occupation account for some, but not all, of the race- and gender-related differences in health status, access to health care, health research, and health care financing. For example, persons with lower income are more likely to report being in fair or poor health. Similarly, the association between poverty and health status can be seen within racial and ethnic groups, but racial and ethnic disparities remain even within income groups.[6] Thus, income does not explain all the racial and ethnic disparities in health status.

Volume I also addresses how poverty affects the ability to obtain health insurance coverage.[7] Again, it was shown that income level has a large effect on the number of individuals who are uninsured or privately insured. However, as this report confirms, race and ethnicity compound the effects of poverty, as demonstrated by differences in insurance rates. Disparities in insurance coverage vary markedly by race and ethnicity beyond the effects of income on that coverage.

Many studies have shown that even when income and other factors (such as age, severity of disease, and health insurance coverage) are taken into account, there are still statistically significant racial differences in health status, treatments received, and other measures of access to health care.[8] Further, other measures of disparity, such as waiting times, should not be affected by gender, race, or ethnicity; yet disparities are found between population groups. Thus, major racial, ethnic, and gender disparities remain in health status and access to health care even after socioeconomic factors are taken into account. These remaining disparities give rise to concerns that discrimination and bias exist in our health care system.

Discrimination and Disparate Impact

The evidence of discrimination by health care providers and insurers is overwhelming. Each volume of this report presents numerous instances where individuals have been either treated differently or denied treatment due to race, national origin, or gender. For example, volume I presents evidence which shows that certain procedures are less frequently prescribed for minorities. Whether this disparate treatment arises directly from the fact that they are minorities or because of other factors which disproportionately affect minorities is a matter of splitting hairs. The effect is the same: discrimination.

This report, particularly in volume II, demonstrates that disparities in health status and access to quality health care may be the result of the disparate impact that certain policies or procedures have on women and members of racial/ethnic groups. Critics of disparate impact theory of discrimination have contended that it is not a valid basis for discrimination charges or complaints. These critics often assume that, in the context of allegations of discrimination relating to a health care provider or insurer, if intentional discrimination is not involved, no legal issue exists. However, the Supreme Court has held that disparate impact is a form of discrimination, prohibited by the implementing regulations of title VI of the Civil Rights Act of 1964 and by

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[5] In 1997, for example, 8.6 percent of white families lived below the poverty line, compared with 26.5 percent of black families, 27.1 percent of Hispanic families, and 14.0 percent of Asian American and Pacific Islander families. U.S. Department of Commerce, Bureau of the Census, "Poverty 1997," accessed at <http://www.census.gov/hhes/poveryty/poverty97/pv97est1.html>. In 1998 the median weekly earnings for white men was $615, compared with $468 for white women and black men, $400 for black women, $390 for Hispanic men, and $337 for Hispanic women. U.S. Department of Labor, Bureau of Labor Statistics, *Employment and Earnings*, January 1999, table 37, accessed at <http://stats.bls.gov/cpsaatab.htm>.

[6] *See* vol. I, figure 2.2.

[7] *See* vol. I, chap. 2.

[8] American Medical Association, Council on Ethical and Judicial Affairs, "Black-White Disparities in Health Care," *Journal of the American Medical Association*, vol. 263, no. 17 (May 2, 1990), pp. 2344–46. *See, e.g.*, G. Caleb Alexander and Ashwini R. Sehgal, "Barriers to Cadaveric Renal Transplantation Among Blacks, Women, and the Poor," *Journal of the American Medical Association*, vol. 280, no. 13 (Oct. 7, 1998), pp. 1148–52 (finding that after adjusting for income, sex, age, cause of renal failure, and years on dialysis, blacks and women were less likely than white men to receive transplants).

title IX of the Education Amendments of 1972.[9] Congress further recognized disparate impact as an appropriate theory of discrimination in the Civil Rights Act of 1991.

The Importance of Physician Diversity and Cultural Competence

Research suggests that minority physicians and dentists are more likely to serve minority patients and communities where a shortage of health care providers exists, and are more likely to provide services at reduced fees. In addition, studies have found that physicians of the same race and/or sex of the patient may be more effective than physicians with different backgrounds from their patients. A recent report in the *Journal of the American Medical Association* stated that both black and white patients feel more involved in their health care when their physicians are of the same race.[10] The result is higher patient satisfaction, increased likelihood that the patient will follow through on treatment, and ultimately better medical care. According to the researchers who conducted the study, these findings suggest that doctors need better training to improve cross-cultural communication.

Cultural barriers in the form of misunderstood customs, the inability to express one's health needs, and lack of trust in the health care system are factors that might hinder a physician's ability to provide adequate treatment to his or her patients. Thus, what this report finds is that, within the context of patient care, it is necessary to open up medical knowledge to include multicultural perspectives to health, health care, and patient-provider interaction. This view does not assume that race is a major determinant of how patients select their doctors or that doctors cannot communicate with people of other cultures. The reason for cultural competency training for health care professionals is to enhance the quality of health care delivery. Cultural competency training is essentially a measure to help medical professionals gain more knowledge about their patients. Further, this report calls for a mandate that health care information be translated into languages for beneficiaries who have difficulty communicating in English, enabling patients to comprehend and participate in the decisions related to health care.

A major finding of the research conducted here is that clearly more minorities are needed as health care professionals. This report supports affirmative action programs that increase the opportunities for minorities in the health professions while maintaining high standards and qualifications for physicians and other health care professionals. For example, the findings in this report suggest that HHS and the Department of Education must support efforts to raise minority students' interest in pursuing medical professions, to increase the academic qualifications of minority students so that they can pursue medical study, and to promote the valuing of diversity within the medical profession.[11]

Affirmative action must be construed more broadly than through the admissions standards for acceptance into medical schools. For instance, initiatives to improve educational opportunities, particularly in math and science, at the elementary, secondary, and postsecondary levels will better prepare all students to pursue medical studies. In conjunction with these initiatives, some of which are illustrated through innovative examples in this report, recruitment efforts can potentially increase the pool of qualified medical school applicants. Thus, rather than suggesting that affirmative action efforts have failed or that admission standards should be lowered, this report indicates that affirmative action efforts should be broadened to include other initiatives.

Volume II of this report highlights the important role the Department of Health and Human Services' Office for Civil Rights must play in promoting initiatives to increase the number of minority physicians. OCR has numerous mechanisms to address issues relating to its civil

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[9] *See* Guardians Assoc. v. Civil Service Comm., 463 U.S. 582 (1983).

[10] Lisa Cooper-Patrick, Joseph J. Gallo, Junius J. Gonzales, Hong Thi Vu, Neil R. Powe, Christine Nelson, and Daniel E. Ford, "Race, Gender, and Partnership in the Patient-Physician Relationship," *Journal of the American Medical Association*, vol. 282 (Aug. 11, 1999), pp. 583–89.

[11] *See* vol. I, chap. 2.

rights enforcement mission. For example, with regard to affirmative action, the report recommends that OCR develop policy guidance to clarify what universities may and may not do under existing law to increase student, faculty, and curricular diversity.[12] In addition, OCR can provide technical assistance and outreach and education to medical schools to assist them in increasing the pool of qualified applicants through extensive recruitment efforts. The fact that numerous universities actively engage in diversity-enhancement programs in itself demonstrates the need for OCR to disseminate guidance on educational institutions' legal responsibilities in this important area.

In addition, the report finds that it is important to encourage girls and women to pursue careers in medicine. Data from the American Medical Association cited in volume I indicate that in 1995 nearly 60 percent of the women practicing medicine were clustered in five areas: internal medicine, pediatrics, family practice, obstetrics/gynecology, and psychiatry.[13] Additional evidence indicates that women face difficulty breaking into medical research careers, further limiting the "choices" available to them. The fact that women physicians are clustered into a few areas of specialties presents a curious phenomenon. While it is true that there is some degree of choice involved in the election of medical specialty, the extent to which women "choose" certain areas is unclear.

Researchers have found subtle signs that many women are discouraged from entering new high-tech medical fields, and there is evidence that women medical students are steered into more "accepted" specialties. For example, one study cited in the report found that of female medical students surveyed, only 8 percent had originally named pediatrics as their chosen specialty, but one-third eventually entered pediatric residencies.[14] This suggests that some occurrence during the course of medical training steered these women toward a field that was not originally intended. The consistent low number of women in certain specialties, including new high-tech medical fields, raises the concern that if this trend continues, the medical profession may become gender identifiable, whereby women are centered in the areas of family medicine and primary care, and men are more concentrated in the new specialized medicines or surgical subspecialties.

Evidence presented here also indicates that women researchers receive a disproportionately smaller share of research funds, compared with their male counterparts. Overall, the report recommends that HHS ensure that funds are awarded in a nondiscriminatory manner. Funding should be based on merit, and both male and female researchers should be provided an equal opportunity to apply for and receive funding. The fact that fewer women apply for grants is one part of the problem which needs to be addressed.

Inclusive Research

Research indicates that minorities and women—particularly minority and poor women—have been excluded from clinical trials for decades. However, this exclusion is not attributed in all cases to discrimination or intentional omission. In some instances, women and minorities have been excluded from trials because the illness under study was thought to be more relevant to men or to certain subpopulations. These medical assumptions (which have sometimes proven erroneous) must be reassessed and based on scientific fact, which cannot be determined unless all populations are studied.

Many women of color, in particular, do not participate in research studies not because of discrimination per se, but because many of them are not informed of such studies or are unaware of the importance of participating in such studies. While the demographic makeup of a community being studied will usually dictate the sample of participants, those residents need to have information about such research. This report strongly urges implementation of Federal, State,

[12] *See* vol. II, chap. 7.

[13] *See* vol. I, chap. 2.

[14] *See* vol. I, chap. 2.

and local education and outreach activities that emphasize the importance of medical research. It does not necessarily advocate special research projects for women and minorities, but rather focuses on strategies to include them in medical research, so that medical findings are applicable to all populations.

The scientific research community acknowledges that women and minorities have been excluded from research, and in recent years emphasis has been placed on the medical necessity of inclusion. As a result, the major research divisions at HHS (National Institutes of Health, Food and Drug Administration, and Centers for Disease Control) have all passed guidelines mandating the inclusion of women in clinical trials.[15] The fact that the issue of including women and minorities in research has become a major political and scientific concern is further proof that there is indeed a problem, and a solution is necessary. In addition to studying female-specific health issues, it is necessary to examine how "gender- neutral" conditions are experienced differently by women and men. If women are not included, the data gathered do nothing to advance the knowledge of those diseases in women.

Conclusion

The recommendations offered by the Commission in this report are largely based on one foundation: the moral belief that, like education, housing, and employment, health care is a fundamental element of the human experience, and should be pursued by all on equal ground. The disparities documented by this report, however, indicate that existing laws have not succeeded in realizing this goal. One critical reason for ineffective enforcement of existing law has been the lack of commitment to equal access to quality health care as a civil right. That is why this report upholds the necessity of a statute that explicitly recognizes health care as occupying the same position of social importance as education, housing, and employment, and that creates an agency to ensure that health care maintains that stature.

In addressing disparities and subtle forms of discrimination infecting our health care system and adversely affecting health care access and outcomes for minorities and women, we as a nation have two options. The first option is to do nothing. Under this plan not a single Federal dollar is spent to conduct civil rights enforcement efforts or to support programs and initiatives designed to reduce these disparities. This option requires the Nation to conceptualize the disparities in our health care system in one of three ways. The first is to simply accept that there have always been disparities in access to employment, education, and even health care, and to ask the question, "Why change now?" The second is to manipulate statistics to show that such disparities do not really exist; so again, we may tell ourselves that no change is needed. Finally, those who actually have access to quality health care can insist that "personal responsibility" and the sense to make "good choices" are the solutions to all of our societal ills. These sentiments justify the abdication of our responsibility as a nation to eradicate discrimination and disparities in the health care system.

The second option it to take action. This option requires that we recognize health as the foundation of our well-being as individuals and our productivity as a nation. To do this we must first develop a national vision for the elimination of disparities in access to *quality* health care, and the subsequent reconciliation of health status between minorities and non-minorities and women and men. This option requires a collaboration between Federal, State, and local governments, as well as private organizations to: (1) raise public awareness of health care as a fundamental component of the Nation's agenda, (2) acknowledge community-specific needs to ensure that all individuals have the opportunity to participate in their own health care, (3) implement initiatives designed to promote access to health care for the underserved, and (4) foster vigorous enforcement of civil rights as the vehicle by which equality in heath care is ultimately achieved.

[15] *See* vol. I, chap. 3.

Acknowledgments

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Chapter 1

Introduction

Equal access to health care for all Americans is a fundamental goal that the Nation has sought to achieve for many years. However, under the existing health care delivery system, there are many people for whom this goal remains unattained. In particular, women and members of racial and ethnic minority groups, especially those with lower socioeconomic status, generally do not have adequate access to quality health care.

Prologue

More than three decades ago, the U.S. Commission on Civil Rights described the treatment received by African Americans in hospitals before the passage of the Civil Rights Act of 1964:[1]

> Prior to 1963, Negro patients at St. Dominic-Jackson Memorial Hospital in Jackson, Mississippi, were housed on the first floor. The hospital's obstetrical ward, delivery room, and nursery were on the second floor of the building. After delivery, Negro mothers were returned to the first-floor Negro ward and their babies were segregated in a separate section of the nursery. Negro fathers could not see their newborn children until they left the hospital because [the fathers] were not allowed on the second floor.[2]

Despite the passage of time, in 1994 the *New York Times* reported that hospitals in New York City were in violation of title VI of the Civil Rights Act because of the practice of segregating maternity ward patients on the basis of their insurance (private versus medicaid).[3] Given that the medicaid patients at these hospitals were primarily minorities, this practice had the effect of segregating new mothers on the basis of race.[4]

There is substantial evidence that discrimination in health care delivery, financing, and research continues.[5] Such discrimination stems from historical inequities; the failure of health care facilities to understand, and Federal agencies to implement, Federal civil rights laws in the health care context; and policies, practices, and pervasive changes in the health care industry that continue to result in a disparate impact on women and minorities. Evidence that discrimination continues to exist in health care suggests that Federal laws designed to address inequality have not been adequately enforced by Federal agencies such as the Office for Civil Rights (OCR) within the U.S. Department of Health and Human Services (HHS). HHS' inability to enforce civil rights laws and OCR's isolation from the rest of the agency and the civil rights community have resulted in the persistence of barriers to access to quality health care for women and minorities.[6]

Access to Health Care in America

Federal statutes created to protect crucial civil rights of all Americans must be vigorously enforced by the agencies entrusted with the implementation of such statutes.

The Federal Government has long sought to address the need for equal access to quality

[1] Pub. L. No. 88–352, 78 Stat. 241 (codified as amended in scattered sections of 42 U.S.C. (1994 & Supp. II 1996)).

[2] U.S. Commission on Civil Rights, *Title VI . . . One Year After: A Survey of Desegregation of Health and Welfare Services in the South*, 1966, p. 5.

[3] Kevin Sack, "Inquiry Finds Hospitals Had 2 Categories," *New York Times*, Apr. 30, 1994, section 1, p. 5.

[4] Arnold Loperena, Patricia Holub, and Victor Hidalgo, equal opportunity specialists, Office for Civil Rights (OCR), Region II, U.S. Department of Health and Human Services (HHS), telephone interview, Feb. 3, 1999, p. 3.

[5] *See generally* chaps. 2–3, and vol. II, chaps. 3–4.

[6] *See* U.S. Commission on Civil Rights, *Federal Title VI Enforcement to Ensure Nondiscrimination in Federally Assisted Programs*, June 1996; Gordon Bonnyman, managing attorney, Tennessee Justice Center, Nashville, TN, telephone interview, Feb. 4, 1999, p. 3.

health care. During the past 35 years in particular, Federal civil rights laws and policies have addressed the need to ensure equal access to health care and nondiscrimination in health care programs for minorities and women. Congress has created several Federal statutes designed to achieve equal protection of the laws through an emphasis on equality of access to institutions, including the Nation's health care system. These statutes have helped to establish the framework for the Federal Government's efforts to eliminate discrimination in the health care delivery system.

Two statutes are particularly relevant to health care: (1) the Hill-Burton Act, formally titles VI and XVI of the Public Health Service Act of 1964;[7] and (2) title VI of the Civil Rights Act of 1964,[8] which has served as a model for more recent civil rights laws affecting health care, such as title IX of the Education Amendments of 1972.[9] These Federal civil rights statutes enacted to fight discrimination on the basis of race, color, national origin, or sex also can have a significant effect on ensuring equal access to quality health care, if enforced.[10] Title VI, one of the most important of these laws, provides that:

> No person in the United States shall, on the ground of race, color, or national origin, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance.[11]

From block grants to States, to research programs funded by the National Institutes of Health (NIH), Federal funds are used in various ways in health care organizations and programs. For example, many hospitals received funds for construction and improvements under the Hill-Burton Act of 1946.[12] The nondiscrimination requirements of the act are still in effect today for hospitals that remain nonprofit organizations.[13] In addition, block grants authorized under the Omnibus Reconciliation Act of 1981[14] provide for nondiscrimination in State and local programs designated in the grants.[15]

Congress has charged various Federal agencies with implementing the nondiscrimination provisions of title VI. HHS is the Federal agency with primary responsibility for enforcing title VI in the health care context, as well as other civil rights statutes and provisions addressing equal access to quality health care. HHS seeks to ensure compliance with the nondiscrimination provisions of these laws by relying on implementing regulations, policy guidance, comprehensive full-scope compliance reviews, complaint investigations, mediation, settlement agreements, technical assistance, outreach, and education programs, and, in some cases, enforcement action. While HHS has striven to accomplish its mission, several significant deficiencies, including a

[7] Pub. L. No. 79–725, 60 Stat. 1040 (1946) (codified as amended at 42 U.S.C. §§ 291–291–o (1994)) (enacting title VI of the Public Health Service Act); Pub. L. No. 93–641, 88 Stat. 2225 (1974) (codified at 42 U.S.C. §§ 300q–300t (1994)) (enacting title XVI of the Public Health Service Act). The Hill-Burton Act was originally designed as a means of facilitating hospital construction, especially in rural communities, when it was first enacted in 1946. In 1964 Congress reformulated Hill-Burton as a key provision in its Public Health Service Act to include the modernization of existing hospital facilities. In 1974 the Hill-Burton Act was amended yet again, this time requiring that facilities prove their necessity and acquire approval from States before receiving funding. Hospitals receiving funds were required to provide a specified amount of service to those unable to pay. Additionally, a facility receiving funds was to be made available to all members of the community in which it was located, regardless of race, color, national origin, or creed. *See* vol. II, chap. 3.

[8] Pub. L. No. 88–352, title VI, 78 Stat. 252 (codified as amended at 42 U.S.C. §§ 2000d–2000d–7 (1994)). *See* vol. II, chap. 3.

[9] Pub. L. No. 92–318, title IX, 86 Stat. 373 (codified as amended at 20 U.S.C. §§ 1681–1688 (1994)).

[10] Commission findings indicate that HHS and the former Department of Health, Education, and Welfare (HEW) have not adequately enforced title VI since its inception. *See* vol. II, chap. 1.

[11] 42 U.S.C § 2000d (1994).

[12] 42 U.S.C. §§ 291–291–o (1994).

[13] Paul Cushing, director, Region III, OCR, HHS, statements at HCFA/Advocates Monthly meeting, Dec. 19, 1998.

[14] Pub. L. No. 97–35, § 901, § 2192(a), §§ 2601–2611, §§ 671–683, § 2352(a), 95 Stat. 357, 535, 543, 552, 818, 893, 511, 867 (1981) (codified as amended at 42 U.S.C. §§ 300w–300w–10; 300x–300x–63; 701–710; 8621–8629; 9901–9926; 1397–1397f (1994 & Supp. II 1996)). The social services block grant, codified at 42 U.S.C. §§ 1397–1397f, does not contain a nondiscrimination provision. The primary care block grant, Pub. L. No. 97–35, sec. 901, §§ 1921–1932, 95 Stat. 357, 552 (codified at §§ 42 U.S.C. §§ 300y–300y10) was repealed in 1988.

[15] Pub. L. No. 97–35, sec. 901, §§ 1908, 1918, sec. 2192(a), § 708, § 2606, § 677, 95 Stat. 357, 542, 551, 825, 900, 516 (codified as amended at 42 U.S.C. §§ 300x–7(a)(1)–(2); 300w–7(a)(1)–(2); 708 (a)(1)–(2); 8625(a); 9906(a) (1994 & Supp. II 1996)).

serious shortage of resources and funding,[16] have hampered its ability to ensure nondiscrimination in health care delivery, finance, and research programs.

Moreover, HHS is presented with innumerable challenges beyond its funding and resource limitations. The U.S. health care system exists in a complex and constantly evolving environment in which widespread discrimination continues to necessitate vigorous enforcement of civil rights statutes. The health care system encompasses hospitals, medical research centers, universities, health care practitioners, managed care organizations, home delivery health organizations, and nursing homes. Lack of access to health care manifests itself in many ways, affecting both the quality and longevity of life. Poor health and high mortality rates among racial and ethnic minority groups are due, in part, to the absence of adequate and accessible health care services in their communities. In addition, racial and ethnic minorities have suffered from medical redlining, which limits the number of doctors and hospitals located in poor and minority communities. Compounding the problem of receiving quality care is the lack of research targeting special needs and concerns of certain populations. Without research concerning the effects of medications on and treatments needed by women and minorities for various conditions, medical professionals may not be able to provide quality care to all individuals.

Women and members of minority groups face several unique health disparities compared with other segments of the population:[17]

- African Americans experience disproportionately high mortality rates from certain causes, including heart disease and stroke, homicide and accidents, cancer, infant mortality, cirrhosis, and diabetes.[18]
- Native Americans are 579 percent more likely to die from alcoholism, 475 percent more likely to die from tuberculosis, and 231 percent more likely to die from diabetes, than the Nation as a whole.[19]
- The primary source of health care for Hispanics is the emergency room. Hispanics are less likely than other groups to have a regular source of care, to be covered by health insurance, and to receive prenatal care.[20]
- Racial and ethnic minorities are more likely than whites to live in areas that are medically underserved.[21] In addition, Hispanic Americans, Asian Americans, and members of other language minority groups face communication and cultural barriers that impede their access to quality health care.[22]
- Many Americans who are among the working poor (primarily women and minorities) are not provided medical coverage by their employers, and, thus, are uninsured.[23]
- Black and Hispanic physicians are more likely than other physicians to treat black, Hispanic, and medicaid or uninsured patients; yet blacks, Hispanics, and other minorities are underrepresented in schools for health professionals.[24]
- The maternal mortality for Hispanic women is 23 percent higher than the rate for non-Hispanic women; black women have a 5 percent higher death rate due to childbirth than non-Hispanic white women.[25]
- Women have less access than men to certain diagnostic and therapeutic procedures, such as kidney dialysis, kidney transplants, and catheterization for coronary bypass surgery.[26]

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[16] *See* vol. II, chap. 2.

[17] *See* chaps. 2–3.

[18] *See* HHS, Health Resources and Services Administration, *Health Care Rx: Access for All*, the President's Initiative on Race, 1998 (hereafter cited as HRSA, *Health Care Rx*).

[19] HHS, Indian Health Service, *1997 Trends in Indian Health*, p. 6.

[20] American Medical Association, Council on Scientific Affairs, "Hispanic Health in the United States," *Journal of the American Medical Association*, vol. 265, no. 2 (Jan. 9, 1991), p. 249 (hereafter cited as AMA, "Hispanic Health").

[21] HRSA, *Health Care Rx*, p. 10.

[22] AMA, "Hispanic Health," p. 248.

[23] HHS, National Center for Health Statistics, *Health, United States, 1998 with Socioeconomic Status and Health Chartbook*, 1998, p. 203 (hereafter cited as NCHS, *Health, U.S., 1998*).

[24] HRSA, *Health Care Rx*, pp. 12–14.

[25] NCHS, *Health, U.S., 1998*, p. 11.

[26] American Medical Association, Council on Ethical and Judicial Affairs, "Gender Disparities in Clinical Decision Making," *Journal of the American Medical Association*, vol. 266, no. 4 (July 24/31, 1991), p. 559.

- Women and members of racial and ethnic minority groups have historically been excluded from clinical trials; thus, insufficient research has been done on their unique health problems.[27]
- Female physicians are concentrated primarily in internal medicine, pediatrics, family practice, obstetrics/gynecology, and psychiatry, and are less likely than males to hold research positions.[28]

Social scientists and legal researchers have produced volumes documenting the inequalities of the health care system. It is through their efforts and the persistence of vocal advocacy groups that have publicized many of these issues, that policymakers, at the Federal, State, and local levels have taken up the health care agenda and made it a central focus of reform initiatives. Reform efforts made over the past decade, although slow, have served as the catalyst for changes in the health care delivery system.

In the 1990s, Congress and the President have proposed major changes to the health care system. Although Congress failed to enact a major health care reform package in 1994, Congress currently is proposing major changes to medicaid as part of its effort to balance the Federal budget. Furthermore, both States and the private sector are moving ahead to implement reforms without waiting for Federal action.[29] It is likely that the pressure to balance the Federal budget and to reform health care delivery at the national, State, and local levels will lead to major changes to medicaid, medicare, and health care delivery over the next few years. Any changes that are implemented are likely to have a great effect on minorities' and women's access to quality health care. At this critical juncture, the Federal Government has an opportunity to create significant positive changes in the Nation's health care delivery system.

Addressing Health Care Disparities and Discrimination

Governmental and Private Reform Efforts

"[N]owhere are the divisions of race and ethnicity more sharply drawn than in the health of our people. . . [n]o matter what the reason, racial and ethnic disparities in health are unacceptable in a country that values equality and equal opportunity for all. And that is why we must act now with a comprehensive initiative that focuses on health care and prevention for racial and ethnic minorities . . ."[30]

In his weekly radio address of February 21, 1998, President William Jefferson Clinton announced a comprehensive Federal initiative to eliminate health care disparities between white and minority Americans by the year 2010.[31] The President detailed nearly a dozen fatal or potentially life-threatening disorders that disproportionately attack African Americans or other minorities, such as Latinos, Asian Americans, and Native Americans. He observed:

> Infant mortality rates are twice as high for African-Americans as for white Americans. African-American men suffer from heart disease at nearly twice the rates of whites. African-Americans are more likely to die from breast cancer and prostate cancer. Overall, cancer fatalities are disproportionately high among both Latinos and blacks. Vietnamese women are five times as likely to have cervical cancer; Chinese-Americans four to five times as likely to have liver cancer. Hepatitis B is much more prominent among Asian-Americans than the rest of the populations. Native Americans suffer higher rates of infant mortality and heart disease. And for diabetes, Hispanic rates are twice the national average, and Native American rates three times the national average.[32]

The President emphasized the need for immediate action to address these disparities and will rely largely on the U.S. Department of Health

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[27] Judith H. LaRosa, Belinda Seto, Carlos E. Caban, and Eugene Hayunga, "Including Women and Minorities in Clinical Research," *Applied Clinical Trials*, vol. 4, no. 5 (May 1995), p. 31. *See also* Lawrence Freedman, et al., "Inclusion of Women and Minorities in Clinical Trials and the NIH Revitalization Act of 1993—The Perspective of NIH Clinical Trialists," *Controlled Clinical Trials*, vol. 16 (1995), pp. 277–85.

[28] American Medical Association, Department of Data Survey and Planning, *Physician Characteristics and Distribution in the US, 1996–97* (Chicago: American Medical Association, 1997), p. 14.

[29] *See* vol. II, chap. 6.

[30] President William Jefferson Clinton, "Radio Address to the Nation," Feb. 21, 1998, accessed at <http://raceandhealth.hhs.gov.>

[31] Ibid.

[32] Ibid.

and Human Services, along with other departments and agencies in the Federal bureaucracy, and at the State and local levels.

Much of the effort to accomplish the goal of eliminating racial/ethnic disparities in health care has focused on the development and implementation of different programs and initiatives. The emphasis on programs to eliminate disparity has been, in many ways, an effective means of addressing the health care needs and concerns of Americans who are confronting discrimination or other barriers to the health care system. For example, by targeting specific groups, these programs have been able to address the differing needs and concerns among racial/ethnic minorities. However, HHS has not effectively integrated the development and implementation of programs and initiatives with civil rights enforcement efforts. As a result, its efforts to eliminate disparities in health care have been largely unsuccessful.

In this report, the Commission explores external factors that affect the success of an agency's civil rights enforcement efforts. The first of these factors relates to OCR's participation within HHS. Nowhere is OCR's involvement more necessary than in initiatives and programs designed to eliminate racial/ethnic or sex disparities in health care. Assessing how HHS has involved OCR in developing and implementing these programs and initiatives is necessary to evaluate OCR's role within the agency. In particular, the extent to which these programs and initiatives include a civil rights component demonstrates whether OCR is being utilized thoroughly. A second factor the Commission explores is the partnership between Federal, State, and local agencies in developing and implementing programs and initiatives to eliminate racial/ethnic and gender disparities in health care. A third factor is the health care reform efforts Congress currently is considering.

These factors reflect the fact that OCR's efforts do not exist in a vacuum. Although OCR is tasked with ensuring civil rights compliance, upholding the mandates of civil rights laws, and working toward the goal of eradicating disparities and discrimination, many other agencies and organizations share these responsibilities. The methods of achieving these objectives vary from agency to agency. For example, OCR relies on policy development, compliance reviews of recipients, complaint investigations, technical assistance, and outreach and education efforts to ensure that racial/ethnic minorities and women will no longer be deprived of equal access to health care. Other agencies within HHS, such as the Office of Minority Health and the Office of Women's Health, use programs and initiatives to fulfill their missions.

In fact, OCR's mission is tied closely to the missions of all the other HHS components, and OCR's interaction with HHS operating divisions (OPDIVS), in particular, is crucial to the success of its mission. HHS operating divisions, as well as State and local agencies and organizations, play an important role in supporting OCR's civil rights enforcement efforts. By working with outside governmental and private agencies, OCR can receive assistance in such activities as compliance reviews, complaint investigations, and technical assistance, outreach, and education. Equally important, OCR can work with these other agencies and organizations to develop and implement programs and initiatives designed to eliminate racial/ethnic disparities in access to quality health care.

By designing programs focusing on the barriers confronting specific racial/ethnic minority groups, HHS and its counterparts at the State and local levels can focus on addressing disparities in health care confronting individuals in each group. Differences among racial/ethnic minorities' experiences, needs, and concerns are evident. One commentator, writing about the "four generally recognized minority groups," Asian Americans and Pacific Islanders, African Americans, Latinos, and Native Americans, noted, "the health care status of minorities varies widely, both within and among groups."[33] For example, "the status of and prejudices against African Americans have different characteristics than those of Mexican Americans, and the biases against the latter group are much more intense in certain areas of the Southwest than in other parts of the country."[34]

Because there are differences within and among minority groups, OCR and other agencies at HHS must embrace diversity. The differing

[33] Herbert W. Nickens, "The Health Status of Minority Populations in the United States," *Western Journal of Medicine*, vol. 155, no. 1 (July 1991), pp. 27–32.

[34] Ibid.

experiences of individuals within distinct groups with distinctive cultures and identities must be recognized to enable the provision of quality, culturally competent health care services. Failure to acknowledge differences and address heterogeneity leads to the perpetuation of ineffective health care practices.

In volume I of this report, the focus is on the role of other HHS, State, and local agencies in developing and implementing programs and initiatives that seek to eliminate disparities in health care. Volume I demonstrates the need to enhance these programs and initiatives through strong civil rights enforcement efforts. First, it highlights the differences in the health status of Americans and reveals the depth of the barriers confronting specific racial/ethnic minorities and women. Second, it shows how programs and initiatives designed to ensure equality in access to health care assist OCR's efforts to combat discrimination by addressing the differing needs and concerns among minority groups.

Civil Rights Enforcement

"So what can we do to eliminate health disparities? We are all in agreement about the need to adopt a comprehensive approach that focuses on a number of areas: research, education of both patients and health care providers, disease prevention and health promotion, measures to ensure that our medical profession reflects the diversity of our nation, and, last, but not least, aggressive enforcement of antidiscrimination laws."[35]

Effective civil rights enforcement efforts can play a significant role in confronting racial/ethnic or sex discrimination and in removing health care disparities. In particular, Federal oversight and monitoring of health care facilities can be a remarkably effective way to ensure that the Nation's health care system is meeting the requirements of civil rights mandates embedded in Federal law. In addition, appropriate outreach and education can ensure that all Americans are familiar with the protections accorded them in these laws.

Strong civil rights enforcement efforts at the Federal, State and local levels are needed if the Nation is to be successful in ensuring equal access to quality health care for every American. In volume II of this report, the Commission evaluates the degree to which OCR has achieved its mission of civil rights protections in health care. Volume II explores factors that affect the quality and effectiveness of an enforcement program, including OCR's approach to conducting enforcement activities. The Commission also assesses OCR's interactions with State health care agencies receiving HHS funds and the effect of those interactions on civil rights enforcement programs.

The Commission also assesses the stature accorded to OCR and its role within HHS, especially its interactions with operating divisions and internal elements, or staff divisions. Of particular significance is the role the operating and staff divisions play in supporting OCR's enforcement efforts. The Commission identifies major deficiencies in all these areas, including the agency's passive approach to enforcement activities and how the overall isolation of OCR within HHS has weakened not only the civil rights enforcement efforts of OCR, but HHS program initiatives.

Overall, it appears, HHS/OCR's enforcement of civil rights laws has been far too weak for far too long to play a significant role in eliminating disparities and discrimination in the U.S. health care system. Based on findings in this report, the Commission makes recommendations to assist HHS in its future civil rights enforcement efforts.

The Commission's Objectives

The Commission seeks to further improve and enhance civil rights enforcement in federally assisted health care facilities, and, in turn, promote nondiscrimination and eliminate barriers to equal access in America's health care system through recommendations for OCR to enforce the law more effectively. With this report, the Commission intends to accomplish the following objectives:

President and Congress

- Advise the President and Congress on OCR's efforts to enforce civil rights laws relating to the provision of health care through an as-

[35] Thomas E. Perez, director, OCR, HHS, statement at the U.S. Commission on Civil Rights, Consultation: Crisis of the Young African American Male in the Inner Cities, Apr. 16, 1999.

sessment of OCR's civil rights enforcement operations.

- Recommend changes in statutory or regulatory law that would improve civil rights enforcement, promote nondiscrimination, and assist in eliminating barriers to equal access to health care in the Nation's health care system.

U.S. Department of Health and Human Services

- Assist HHS in improving its efforts to enforce civil rights and promote equal access to health care in service delivery, financing, and research.
- Offer recommendations for the improvement of HHS' existing efforts to implement and enforce civil rights laws.
- Provide HHS with new perspectives on health care through a summary of contemporary literature on health care, and by reporting experiences of members of minority communities and women in the health care system.
- Report on civil rights efforts undertaken at the State and local levels and recommending ways HHS can continue to improve civil rights efforts in dealing with State and local health care agencies.

State and Local Health Care Agencies and Health Care Recipients

- Clarify and assess the responsibilities of State and local health care agencies under the law and under HHS regulations.
- Emphasize for State and local health care agencies and health care funding recipients (including hospitals, nursing homes, home health care agencies, managed care systems) the continuing need for strong civil rights enforcement by presenting a discussion of the experiences of members of minority communities and women in the health care system.
- Assist State and local health care agencies in improving their mechanisms to address civil rights enforcement.
- Assist in identifying barriers to equal health care access by providing suggestions and examples of how civil rights considerations should be factored into the development, implementation, and modification of health care programs.
- Encourage State and local health care agencies and HHS funding recipients to make civil rights a primary consideration to ensure that all individuals have equal access to health care programs.

General Public

- Increase understanding of civil rights perspectives relating to health care programs.
- Increase awareness among the public of the inequities many people face in gaining access to quality health care.

Beneficiaries of Federally Funded Health Care

- Work to ensure that members of minority communities and women receive health care delivery in a nondiscriminatory manner by assisting in the improvement of civil rights enforcement at the Federal, State, and local levels.
- Facilitate the development of health care delivery, financing, and research programs that help each individual, regardless of race, color, national origin, or sex to receive the same high-quality health care.
- Work to ensure that all individuals, regardless of race, color, national origin, or sex, will not unnecessarily suffer from debilitating and potentially life-threatening effects because of unlawful discrimination in the provision of health care services.

Finally, the Commission intends to use this report to ensure that no one will be relegated unfairly to poor quality health care; that members of minority communities and women will be included in health care research studies; and that they will not be accorded any lesser quality of care based on their relative inability to pay for health care services due to their race, color, national origin, or sex.

Chapter 2

Background: Disparities, Discrimination, and Diversity in Health Care

"Health care is more than just a peculiar struggle over who gets what kind of care and who gets stuck with the bill. . . . [H]ealth care is an ethical and moral matter. Lack of access to adequate health care can restrict an individual's normal range of opportunities and raises basic issues of fairness and social justice."[1]

Access to health care is affected by several factors: availability and quality of health care services (medical facilities, hospitals, nursing homes, medical personnel, etc.), availability and affordability of financing (managed care, private insurance, medicare/medicaid, etc.), and the extent of medical research (clinical trials, research on the causes and consequences of diseases, etc.). These factors, because they affect access to health care, ultimately affect the health status of women and minorities. The extent to which problems in access are the result of discrimination or improper administration must be addressed.[2]

The U.S. Department of Health and Human Services (HHS), the agency responsible for enforcing civil rights laws relating to health care, recognizes that unequal access to health care is a nationwide problem:

> [D]espite notable progress in the overall health of the Nation, there are continuing disparities in the burden of illness and death experienced by blacks, Hispanics, American Indians and Alaska Natives, and Pacific Islanders, compared to the U.S. population as a whole. The demographic changes that are anticipated over the next decade magnify the importance of addressing disparities in health status. Groups currently experiencing poorer health status are expected to grow as a proportion of the total U.S. population; therefore, the future health of America as a whole will be influenced substantially by our success in improving the health of these racial and ethnic minorities. A national focus on disparities in health status is particularly important as major changes unfold in the way in which health care is delivered and financed.[3]

HHS has also recognized the importance of looking at gender-based disparities in health care. According to the National Institutes of Health (NIH):

> Women's health issues in general, and women's health care needs in particular, are foremost among the Nation's public health priorities. Meeting the health care needs of women requires a comprehensive understanding of several interrelated issues, including: the social, cultural, economic and physical environments of women; financial access to health care services; provider awareness of the need for women's health services; and the content, quality and outcomes of health services provided to women.[4]

Despite the Department's apparent concern for women's and minorities' health issues, HHS' Office for Civil Rights (OCR) generally has failed to enforce civil rights laws vigorously and appropriately.[5] Thus, there remain disparities in ac-

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[1] David Barton Smith, *Health Care Divided: Race and Healing A Nation* (Ann Arbor, MI: University of Michigan Press, 1999), p. 9.

[2] David Barton Smith, "Addressing Racial Inequities in Health Care: Civil Rights Monitoring and Report Cards," *Journal of Health Politics, Policy & Law*, vol. 23, no. 1 (February 1998), pp. 75–105 (hereafter cited as Smith, "Racial Inequities").

[3] U.S. Department of Health and Human Services (HHS), "Eliminating Racial and Ethnic Disparities in Health: Overview," accessed at <http://raceandhealth.hhs.gov/over.htm> (hereafter cited as HHS, "Eliminating Racial and Ethnic Disparities").

[4] HHS, National Institutes of Health, "Health Care for Women: Access, Utilization, Outcomes, January 1990 thru July 1993," 1993.

[5] *See* U.S. Commission on Civil Rights (USCCR), *The Health Care Challenge: Acknowledging Disparity, Confronting Discrimination, and Ensuring Equality, Vol. II. The Role of Federal Civil Rights Enforcement Efforts*, September 1999, chap. 1 (hereafter cited as USCCR, *The Health Care Challenge*, vol. II).

cess to health care, disparities in health research, and unequal distribution of health care financing in the United States. HHS has acknowledged these disparities and has publicly committed itself to eliminating disparities in health status by the year 2010, through its Healthy People 2010 objectives:

> Compelling evidence that race and ethnicity correlate with persistent, and often increasing, health disparities among U.S. populations demands national attention. . . . These disparities are even greater if comparisons are made between each racial and ethnic group and the white population. . . . These disparities are not acceptable. We must do more than work toward reduction; we must work toward elimination.[6]

Nonetheless, initiatives alone cannot improve the health of the Nation. To address issues related to unequal access to health care, HHS must focus its attention on vigorous civil rights enforcement.

The failure of HHS/OCR to play an active role in the monitoring and regulation of health care has resulted in the continuance of policies and practices that, in many instances, are either discriminatory or have a disparate impact on minorities and women. OCR must be actively involved in addressing health care issues that can potentially result in unequal access to and receipt of *quality* health care. Failure to do so results in an unstated acceptance of poor or nonexistent health care for minorities and women, and a perpetuation of inequality in the United States.[7]

A Profile of Health Status in the U.S.

"There are significant inequalities in health status among Americans. Racial and ethnic minorities living in the United States bear a disparate burden of death and illness as compared with the population as a whole. They are more likely to suffer from chronic and disabling conditions such as hypertension and cancer and to die prematurely. . . Of all minority groups, African Americans are in the poorest health. Compared to white Americans, African Americans are disadvantaged at every stage of life, from cradle to grave."[8]

A look at the health status of minorities and women reveals the importance of civil rights laws to the health care system. Unequal access to health care services, financing, and research translates into racial, ethnic, and gender differences in health in the United States. Inequalities in income, education, and occupation account for some of differences in health status and access to health care, but these factors are not the only ones.[9] Inequities, based on gender, race, and ethnicity, abound in the health care system.[10] Health care reform is required to address these issues.

To be effective, health care reforms and other health-related legislation must focus on improving health status in the United States.[11] However, health status is intimately linked to race, ethnicity, and gender. Thus, programs that do not consider racial, ethnic, and gender variations in health, income, etc., run the risk of continuing or widening such disparities. For example, some commentators contend that the administration of medicaid and medicare have the potential for racial bias, and thus unequal treatment.[12] According to one study:

> Because racial minorities are overrepresented among older persons living in poverty, health policies that hurt low-income elders will correspondingly worsen the racial gap in receipt of health care. Proportionally

[6] HHS, Office of Public Health and Science, *Healthy People 2010 Objectives: Draft for Public Comment*, Sept. 15, 1998, Goals, pp. 19–20 (hereafter cited as HHS, *Healthy People 2010 Objectives*).

[7] *See generally* USCCR, *The Health Care Challenge*, vol. II, chaps. 3, 4, and 5, for an indepth discussion of deficiencies in OCR's enforcement efforts.

[8] Jane Perkins, "Race Discrimination in America's Health Care System," *Clearinghouse Review*, special issue, 1993, p. 372, citing U.S. General Accounting Office, *Census Reform: Early Outreach and Decisions Needed on Race and Ethnic Questions*, GAO/GGD–93–36, January 1993, pp. 2–3.

[9] H. Jack Geiger, "Race and Health Care—An American Dilemma?" *New England Journal of Medicine*, vol. 335 (Sept. 12, 1996), pp. 815–16.

[10] *See* chap. 3.

[11] Vernellia R. Randall, "Does Clinton's Health Care Reform Proposal Ensure Equality of Health Care for Ethnic Americans and the Poor?" *Brooklyn Law Review*, vol. 60 (spring 1994), p. 167. *See also* Stephen P. Wallace, Vilma Enriquez-Haas, and Kyriakos Markides, "The Consequences of Color-Blind Health Policy for Older Racial and Ethnic Minorities," *Stanford Law & Policy Review*, vol. 9 (spring 1998), pp. 329–40 (hereafter cited as Wallace et al., "Color-Blind Health Policy").

[12] *See generally* Wallace et al., "Color-Blind Health Policy."

more older minorities than older whites will be affected by increases in out-of-pocket spending requirements, making it more difficult for them to obtain the necessary medical care. The increasing shift to Medicare managed care holds uncertain consequences for minority elders.[13]

Thus, failure to recognize differences in health care delivery, financing, and research are discriminatory barriers to health care access and create and perpetuate differences in health status.[14]

Indicators of Health Status

There are several indicators of health status.[15] Among these are death rates, disease rates, and self-assessment of health status, which are discussed below. However, researchers have noted that "[h]ealth status is a complex concept and difficult to measure."[16] Thus, statistical indicators must be used with caution when "policy questions of equity and resource allocation are to be decided using indicators of health status."[17] Nonetheless, a review of the indicators of health status suggests areas where there are disparities in health care by race, ethnicity, and gender and unequal access to quality health care services, health care financing, and medical research.

Several indicators of health status show disparities among racial and ethnic groups, and by gender. One of the most glaring examples of disparity in health status is the difference in age-adjusted death rates for various segments of the U.S. population. As shown in appendix 2.1, the total annual death rate (deaths from all causes) is 491.6 deaths per 100,000 people.[18] However, the death rate for males is 623.7 and for females only 381.0. Similarly, blacks have a much higher death rate (738.3) than all other race/ethnic categories. Asian Americans/Pacific Islanders have the lowest death rate (277.4).[19]

Death rates for certain diseases and other causes also vary greatly by race and ethnicity.[20] For example, the death rate for diabetes for blacks (28.8) and American Indian/Alaska Natives (27.8) is more than twice that of whites (12.0), and greater than that of other minority groups.[21] Note that blacks have the highest death rates for 15 of the 20 causes of death listed in appendix 2.1. Blacks are significantly more likely to die from heart disease, cancer, HIV, and homicide/legal intervention, than are other groups.[22]

Similarly, estimates of life expectancy vary by race and gender.[23] Figure 2.1 shows the changes in life expectancy at birth since 1900. Although life expectancy for all Americans has increased by almost 30 years since the turn of the century, there are still great differences by race and gender.[24] Women, overall, can expect to live longer than men, but while white women have an average life expectancy of 79.7 years, the average life expectancy for black women is 74.2 years. White

[13] Ibid., p. 338.

[14] *See generally* Wallace et al., "Color-Blind Health Policy." *See also* American Medical Association, Council on Ethical and Judicial Affairs, "Black-White Disparities in Health Care," *Journal of the American Medical Association*, vol. 263, no. 17 (May 2, 1990), pp. 2344–46 (hereafter cited as AMA, "Black-White Disparities"); American Medical Association, Council on Ethical and Judicial Affairs, "Gender Disparities in Clinical Decision Making," *Journal of the American Medical Association*, vol. 266, no. 4 (July 24/31, 1991), pp. 559–62 (hereafter cited as AMA, "Gender Disparities").

[15] Ronald M. Andersen, Ross M. Mullner, Llewellyn J. Cornelius, "Black-White Differences in Health Status: Methods or Substance?" *Milbank Quarterly*, vol. 65, suppl. 1 (1987), p. 72.

[16] Ibid., p. 76.

[17] Ibid., p. 97.

[18] The death rate represents the number of deaths in a population divided by the total population at mid-year. Death rates are expressed as the number of deaths per 100,000 people. The age-adjusted death rate is calculated using age-specific death rates per 100,000 population rounded to the 1 decimal place. Age adjustment is the application of age-specific rates in a population to a standardized age distribution to eliminate differences in observed rates that result from age differences in population composition. HHS, National Center for Health Statistics, *Health, United States, 1998 with Socioeconomic Status and Health Chartbook*, 1998, app. II, pp. 419, 442 (hereafter cited as NCHS, *Health, U.S., 1998*). *See also* app. 2.1.

[19] Ibid., p. 203. *See also* app. 2.1.

[20] Ibid. *See also* app. 2.1.

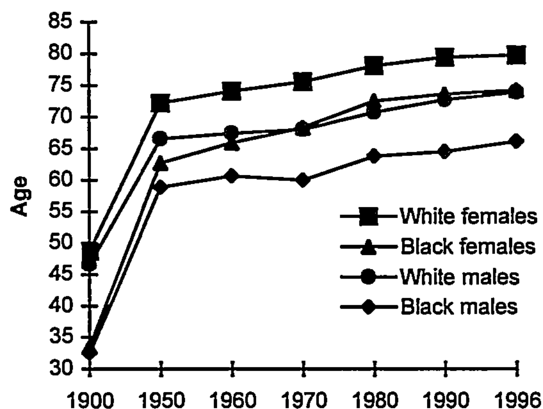
[21] Ibid. *See also* app. 2.1.

[22] Ibid. *See also* app. 2.1.

[23] HHS, Public Health Service, Health Resources and Services Administration, *Health Status of Minorities and Low-Income Groups: Third Edition*, 1991, p. 16 (hereafter cited as HRSA, *Health Status of Minorities*).

[24] NCHS, *Health, U.S., 1998*, p. 200.

Figure 2.1
Life Expectancy at Birth, 1900–1996



SOURCE: U.S. Department of Health and Human Services, National Center for Health Statistics, *Health, United States, 1998 with Socioeconomic Status and Health Chartbook,* 1998, p. 200.

males can expect to live 73.9 years, compared with only 66.1 years for black males.[25]

Another indicator of health status is self-assessed health. This measure, which includes physical, emotional, and personal components of health, has been shown to be a valid measure of health status and a good indicator of mortality.[26] According to the National Center for Health Statistics (NCHS), black and Hispanic persons are more likely to rate themselves as being in fair or poor health than are white persons. NCHS notes, however, that within race and gender groups, health assessments are related to income.[27] As shown in figure 2.2, those in higher income groups are least likely to report having fair or poor health, while those in the lower income groups are most likely to report fair or poor health.[28]

Recognizing these obvious disparities is the first step toward searching for explanations and then finding solutions. Such disparities may be caused by socioeconomic, biological, or cultural factors; the nature of the health care industry; institutionalized forms of discrimination; or facially neutral policies which result in an adverse impact on certain groups. Although HHS is making extensive efforts to address disparities in health care status and access to health care, the disparities persist. Such startling disparities, no matter who is at a disadvantage, are cause for concern. Thus, it is critical to determine if such disparities are the result of civil rights violations, or other systemic problems in the Nation. It is HHS/OCR's mission to analyze disparities in health status and health care access from the civil rights perspective, a task which it has yet to fully accomplish.

Disparities in Health Status by Race/Ethnicity

To better understand disparities in health status, it is important to look at differences in disease prevalence rates, health care service utilization, and other indicators of access to quality health care services. There are many tangible indicators of the differences in health status by race and ethnicity in the United States. According to statistics compiled by HHS:

- Infant mortality rates are 2½ times higher for blacks than for whites, and 1½ times higher for American Indians than for whites.
- Black men under age 65 have prostate cancer at nearly twice the rate of white men under age 65.
- The death rate for heart disease for blacks is higher than for whites (147 deaths per 100,000, compared with 105 deaths per 100,000).
- Individuals from racial and ethnic groups account for more than 50 percent of all AIDS cases, although they account for only about 25 percent of the U.S. population.
- The prevalence of diabetes among American Indians and Alaska Natives is more than twice that for the total population; diabetes rates are 70 percent higher for blacks than for whites, and the rate among Hispanics is twice that of whites.
- Black children are three times more likely than white children to be hospitalized for asthma.

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[25] Ibid. For an explanation of women's longer life expectancy compared with men, *see* "Disparities in Health Status by Gender" below.

[26] Ibid., p. 102.

[27] Ibid.

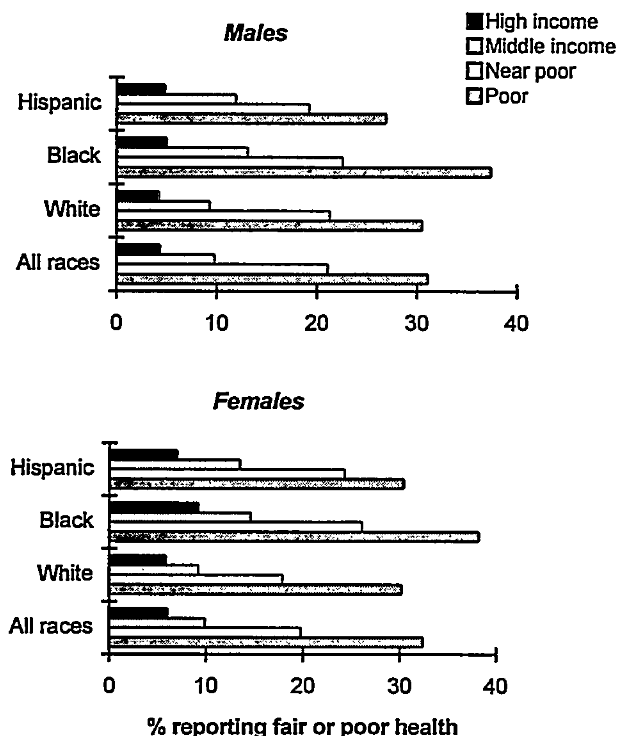
[28] Ibid., p. 154.

- Racial and ethnic minorities are more likely than whites to live in medically underserved areas.[29]

Similar to death rates, incidence rates for certain conditions vary by race and ethnicity. For example, according to the 1995 National Health Interview Survey, among persons 46 to 64 years old, blacks report higher incidence rates of arthritis, visual impairments, ulcers, diabetes, anemia, and high blood pressure. Whites have a higher incidence of hearing impairments, orthopedic impairments, and heart disease.[30] Among American Indians ages 25 to 44, the leading causes of death are accidents and chronic liver disease; for ages 45 to 54, the leading causes of death are diseases of the heart and malignant neoplasms.[31] An alarming difference in incidence rates can be seen in the number of cases of acquired immunodeficiency syndrome (AIDS). Although the spread of the disease is decreasing in some groups, it is increasing in others. For example, the number of new cases for black men exceeds the number of new cases for white men.[32] The incidence rate of AIDS is greater for blacks and Hispanics than for other groups.[33] The ratio of AIDS cases to the population for black men is almost seven times that of white men. Asian Americans and Pacific Islanders have the lowest prevalence of AIDS.[34]

According to one study, although the health of minorities, senior citizens in particular, is worse than that of whites, older minorities often do not have the same access to health insurance as their white counterparts.[35] Although medicaid

Figure 2.2
Fair or Poor Health Status among Adults 18 Years and Older by Race and Income, 1995



SOURCE: U.S. Department of Health and Human Services, National Center for Health Statistics, *Health, United States, 1998 with Socioeconomic Status and Health Chartbook*, 1998, p. 154

[29] HHS, Health Resources and Services Administration, *Health Care Rx: Access for All*, the President's Initiative on Race, 1998, pp. 2–10 (hereafter cited as HRSA, *Health Care Rx*). *See* app. 2.2. The term "underserved" is defined as when the percentage a group of patients (e.g., minority or medicaid) constitutes in a hospital's service population is significantly less than the percentage the group constitutes in the hospital's user population. Conversely, a group of patients is "overserved" if the percentage the group constitutes in a hospital's service population is significantly greater than the percentage the group constitutes in the hospital's user population. A hospital's "service population" often refers to all inpatients receiving service from the hospital regardless of where they reside. A hospital's "user population" is the totality of persons who reside in the hospital's service area and who use the inpatient services of any acute care hospital during a specified time period. HHS, Office for Civil Rights (OCR), "Analysis of Civil Rights Data Training Workbook," April 1998, pp. 11–12 (hereafter cited as OCR, "Analysis of Civil Rights Data Training Book").

[30] HHS, Centers for Disease Control and Prevention, National Center for Health Statistics, "Current Estimates from the National Health Interview Survey, 1995," Vital and Health Statistics, series 10, no. 199 (October 1988), pp. 81–82. Incidence rates are reported as the number of reported conditions per 1,000 persons. Ibid.

[31] HHS, Indian Health Service, *1997 Trends in Indian Health*, pp. 58–59 (hereafter cited as IHS, *1997 Trends in Indian Health*).

[32] HRSA, *Health Care Rx*, pp. 2–3.

[33] NCHS, *Health, U.S., 1998*, p. 265.

[34] Ibid.

[35] Robert H. Binstock, "Public Policies and Minority Elders," Jan. 27, 1998, p. 10, prepared as a chapter for May L. Wykle and Amasa B. Ford, eds., *Serving Minority Elders in the 21st Century* (New York: Springer Publishing Company, in press).

and medicare fill some of the gap, concerns remain over the quality of care older minorities receive. The author states, "Policy trends focused on limiting governmental expenditures on Medicare and Medicaid suggest that access to and quality of care financed by these programs may become diminished generally and, perhaps, especially so for minorities."[36] The author also noted that "[t]he health care safety net for older members of minority groups may also be weakened by the contemporary policy trends that focus on controlling the costs of long-term care reimbursements paid by Medicare and Medicaid."[37]

As shown in table 2.1, there also are great differences in birthweights and infant mortality rates. Blacks have the highest prevalence of low-birthweights of all racial and ethnic categories.[38] In 1995, 13.1 percent of African American babies had a low birthweight, which is defined as weighing less than 5.5 pounds. Comparatively, less than 7 percent of the babies of other racial/ethnic categories had a low birthweight.[39]

Table 2.1

Percentage of Low Birthweight Births and Infant Mortality Rates by Race and Hispanic Origin, 1995

Race and Hispanic Origin	% of births with low birthweight	Infant mortality rate
White	6.2	6.3
Black	13.1	14.6
American Indian/Alaska Native	6.6	9.0
Asian/Pacific Islander	6.9	5.3
Chinese	5.3	3.8
Japanese	7.3	5.3
Filipino	7.8	5.6
Hawaiian and part Hawaiian	6.8	6.5
Other Asian or Pacific Islander	7.1	5.5
Hispanic	6.3	6.3
Mexican American	5.8	6.0
Puerto Rican	9.4	8.9
Cuban	6.5	5.3
Central and South American	6.2	5.5
Other and unknown Hispanic	7.5	7.4

SOURCE: Federal Interagency Forum on Child and Family Statistics, *America's Children: Key National Indicators of Well-Being,* 1998 (Washington, DC: Government Printing Office) (NCES 98–140), pp. 80–81.

An interesting paradox, however, is the fact that children born to recent immigrants have rates of low birthweights that are lower than for those who are born to individuals who have been in the United States for more generations.[40] This is true for most subgroups of Hispanic and Asian immigrants. While the reasons for this phenomenon have not yet been clearly documented, it has been speculated that examination of lifestyle differences, such as nutrition and stress, could shed some light on these differences, despite the fact that immigrants tend to also have lower rates of prenatal care.[41]

Infant mortality rates also vary significantly by race and ethnicity.[42] The infant mortality rates for both white and Hispanic infants is 6.3 deaths per 1,000 births (see table 2.1). The mortality rate for black infants, 14.6 per 1,000, is more than twice the infant mortality rate of

[36] Ibid., p. 11.

[37] Ibid., p. 12.

[38] Federal Interagency Forum on Child and Family Statistics, *America's Children: Key National Indicators of Well-Being,* 1998 (Washington, DC: U.S. Government Printing Office) (NCES 98–140), p. 80. There is relatively little information available on the health status of children in certain minority groups, particularly immigrants. Children in immigrant families are the fastest growing component of the child population. Although a recent Presidential Executive order mandates the Federal Interagency Forum on Child and Family Statistics to publish an annual report on children, there is still very little public dissemination of information on even the most basic indicators of the conditions and well-being of children in immigrant families.

Few national information systems collect the full array of data needed on country of origin and immigrant status; few have samples large enough to support conclusions for more than three or four specific countries of origin; and none has progressed significantly in collecting information on aspects of healthy development and adjustment that may be unique to children in immigrant families. Thus, most conclusions regarding children in immigrant families in the United States must be viewed as first steps toward acquiring more definitive knowledge. Donald J. Hernandez and Evan Charney, eds., *From Generation to Generation: The Health and Well-Being of Children in Immigrant Families* (Washington, DC: National Academy Press, 1998), p. 15.

[39] Federal Interagency Forum on Child and Family Statistics, *America's Children,* p. 80.

[40] Hernandez and Charney, *From Generation to Generation,* p. 60.

[41] Ibid, pp. 60–61.

[42] The infant mortality rate is defined as the number of infant (under 1 year of age) deaths per 1,000 lives births. Federal Interagency Forum on Child and Family Statistics, *America's Children.*, p. 81.

whites and Hispanics. The American Indian/Alaska Native infant mortality rate (9.0) is also higher than that of whites and Hispanics. Asian Americans and Pacific Islanders have the lowest infant mortality rate (5.3).[43]

Disparities in Health Status by Gender

One of the most obvious differences in health indicators between men and women is life expectancy. As noted earlier, women can expect to live on average 5.8 years longer than men.[44] The longer life expectancy for women may appear at first to contradict claims that women face difficulty accessing health care and, in general, have fewer health needs met. However, the reasons for women's longevity can be explained by many factors, and may not necessarily indicate better health status. Women appear to experience more disease and disability than men throughout most of their lifespan.[45] Men tend to develop more serious illnesses much earlier in life and die from them at an earlier age, whereas women are 11 times more likely to have acute or short-term illnesses.[46] The contradiction of lower mortality but higher morbidity has been the subject of much investigation.[47] While there is no clear explanation, several factors have been attributed to longer life expectancy.

Women tend to live longer than men because they take more preventive measures in avoiding poor health.[48] Sociologists have argued that women more readily admit that they are sick and consult with physicians more often.[49] Women are also less likely to adopt unhealthy lifestyle behaviors, including smoking, alcohol consumption, and illegal drug use.[50] In addition, high rates of death from coronary heart disease in men have been attributed to high stress occupations.[51] Women are also less likely to die from accidents, including automobile accidents, and firearm homicide.[52] Higher accident rates among men may be attributed to exposure to jobs or other activities where the risk of death or injury is higher.[53]

Further, the predominant causes of male mortality result in more sudden death, whereas women typically die from diseases that consume wider timeframes before death. In 1995 patterns in the leading causes of death varied by sex. For males and females 7 of the 10 leading causes of death were the same, but differed by rank. While accidental death was the fourth leading cause of death for males, it was the seventh leading cause for females. Suicide and homicide were ranked 9th and 10th respectively among men, but were not ranked among the 10 leading causes of death for women.[54]

Men and women display differences in other health status indicators (aside from life expectancy), as well as different tendencies toward use of health care services, which result in disparities in the type of care received. There are several indicators of disparities in health status between men and women. The Agency for Health Care and Policy Research provides examples of the results of studies it has supported:

- Women are 20 percent more likely than men to die from a heart attack.
- Women receive less aggressive treatment than men following a heart attack.
- Women are 1.6 times more likely then men to die after coronary angioplasty.
- More women than men require bypass surgery or suffer a heart attack after angioplasty.
- Women are less likely than men to receive life saving drugs, such as aspirin, beta blockers, or lidocaine, for heart attacks.
- Women with AIDS receive fewer health care services than men.

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[43] Ibid.

[44] *See* "Indicators of Health Status" above.

[45] Carol S. Weisman, *Women's Health Care* (Baltimore, MD: The Johns Hopkins University Press, 1998), p. 96.

[46] Kenneth C.W. Kammeyer, George Ritzer, and Norman R. Yetman, *Sociology: Experiencing Changing Societies Sixth Edition* (Boston, MA: Allyn and Bacon, 1994), p. 479 (hereafter cited as Kammeyer et al., *Sociology: Experiencing Changing Societies*).

[47] Weisman, *Women's Health Care*, p. 96.

[48] Kammeyer et al., *Sociology: Experiencing Changing Societies*, p. 480.

[49] Ibid.

[50] Ibid., p. 479.

[51] Ibid.

[52] Ibid., p. 480.

[53] Ibid.

[54] HHS, Centers for Disease Control and Prevention, National Center for Health Statistics, "Monthly Vital Statistics Report," vol. 45, no. 11, suppl. 2 (June 12, 1997), accessed at <http://www.cdc.gov/nchswww/data/mv451152.pdf>.

- Women are less likely than men to receive major diagnostic procedures.
- Women are less likely than men to be correctly diagnosed with tuberculosis.[55]

There are several explanations for gender differences in health status. Experts in health research acknowledge that women's health issues often have been overlooked,[56] despite documentation of significant differences between men's and women's health. Some commentators have linked these differences to discrimination. According to an article in the *New England Journal of Medicine*, women's access to health care can be dependent upon their relationships with men.[57] Two commentators stated, "Adequate access to health care for women requires that they be married to men who do not abuse them or that they have well-paying jobs, hold public office, or occupy other positions of power, access to which is impeded by institutional biases in favor of men."[58]

Other authors have noted the link between gender and race and ethnicity. For example, one author contends that women of color often have low-paying jobs with no insurance, and thus are likely to have poorer health than other women or men. For minority women, health status is affected by income, employment, and other threads in the "fabric of oppression."[59] The author notes:

Many Puerto Rican and Asian-American women work in the textile industry under sweatshop conditions. They spend grueling hours in poorly ventilated rooms, working with toxic chemicals. Others work in the health care industry where they are harmed by their proximity to anesthetic gases and X-rays. They harm themselves by performing heavy lifting. Authorities estimate that 75 percent of migrant farmworkers are Mexican-American and another 20 percent are black. Many of these, of course, are women—women who work and live in an environment filled with pesticides.[60]

Socioeconomic Factors and Health Status

"Whether the racial disparities in treatment decisions are caused by differences in income and education, sociocultural factors, or failures by the medical profession, they are unjustifiable and must be eliminated. Not only do the disparities violate fundamental principles of fairness, justice, and medical ethics, they may be part of the reason for the poor quality of health. . .in the United States."[61]

Several studies have shown that access to health care is associated with improved health outcomes.[62] However, experiences with health care services delivery appear to differ significantly by race, ethnicity, and gender. Moreover, overall health status among racial and ethnic minority groups and women underscores significant problems in access to health care.

The U.S. Department of Health and Human Services (HHS) has been regularly tracking the health status of disadvantaged populations since the 1970s.[63] In 1985 HHS noted:

Despite the unprecedented explosion in scientific knowledge and the phenomenal capacity of medicine to diagnose, treat, and cure disease, Blacks, Hispanics, and Native Americans, and those of Asian/Pacific Islander heritage have not benefited fully or equitably from the fruits of science or from those systems responsible for translating and using health sciences technology.

. . . Although tremendous strides have been made in improving the health and longevity of the American people, statistical trends show a persistent, distress-

[55] HHS, Agency for Health Care Policy and Research, "AHCPR Women's Health Highlights," accessed at <http://www.achpr.gov/research/womenh1.htm#new1> and <http://www.achpr.gov/research/womenh2.htm#order>.

[56] Nicole Lurie et al., "Preventive Care for Women—Does the Sex of the Physician Matter?" *New England Journal of Medicine*, vol. 329 (Aug. 12, 1993), pp. 478–82.

[57] Steven Miles and Kara Parker, "Men, Women, and Health Insurance," *New England Journal of Medicine*, vol. 336 (January 1997), pp. 218–21.

[58] Francoise Baylis and Hilde Lindemann Nelson, "Access to Health Care for Women," *New England Journal of Medicine*, vol. 336 (June 19, 1997), p. 1841.

[59] Judy Scales-Trent, "Women of Color and Health: Issues of Gender, Community, and Power," *Stanford Law Review*, vol. 43 (July 1991), pp. 1359–60. *See* "Women of Color" below.

[60] Scales-Trent, "Women of Color and Health," p. 1359 (citations omitted).

[61] AMA, "Black-White Disparities in Health Care," p. 2346.

[62] Peter Franks, Martha R. Gold, and Carolyn M. Clancy, "Use of Care and Subsequent Mortality: The Importance of Gender," *Health Services Research*, vol. 31, no. 3 (August 1996), pp. 347–63.

[63] HRSA, *Health Status of Minorities*, p. 5.

ing disparity in key health indicators among certain subgroups of the population.[64]

These disparities in health status persist almost 15 years later.

Several socioeconomic factors influence the analysis of disparities in health care and health status relating to race, ethnicity, and gender.[65] Any discussion of socioeconomic status in the United States requires a discussion of race/ethnicity and gender, since these factors are entwined in complex, inextricable ways.[66] Inequalities in education, income, and occupation, the primary determinants of socioeconomic status, account for some of the race- and gender-related differences.[67] For example, individuals with lower incomes and less education (usually women and members of racial/ethnic groups) have higher death rates than better educated, wealthier persons, and the differences between these groups are increasing.[68] HHS has noted the relationship between health status and socioeconomic indicators:

> Income- and education-related differences in knowledge and time to pursue healthy behaviors, adequate housing, nutritious foods, safe communities to live in, and healthy environments to work in may influence the health and well-being of Americans in different socioeconomic positions. Certainly the stresses and strains of individuals with lower incomes imposes an emotional and psychological cost that is reflected in poorer health. Alternatively, individuals with higher education may have greater exposure to health related information that assists them in adopting health promoting behaviors.[69]

Data compiled by NCHS confirm that health status, health-related behaviors, health care access, and health care utilization are related to socioeconomic characteristics, such as income, educational attainment, and occupation, all of which vary by race, ethnicity, and gender.[70] Education, income, and occupation are related to many measures of health status.[71]

Education

Educational attainment varies by age, race, and ethnic origin. Whites and Asian Americans/Pacific Islanders are more likely than blacks and Hispanics to have more than 12 years of education. Further, 44 percent of Hispanics have less than 12 years of education. Only about 15 percent of blacks have a college degree, compared with 28 percent of whites and 45 percent of Asian Americans/Pacific Islanders[72] (see appendix 2.2). Although Asian Americans/Pacific Islanders have high educational attainment as a whole, variation is great among the various ethnic subgroups.[73]

According to NCHS, education influences health through cultural, social, and psychological means. For example, education can increase exposure to information about health and disease prevention.[74] Education can also be linked to health-related behaviors such as getting prenatal care. In 1996, among women with 16 or more years of education, 94.7 percent of white women and 88.9 percent of black women received prenatal care during the first trimester of pregnancy.[75] Less than 70 percent of women with less than a high school education received prenatal care.[76]

Death rates for chronic diseases, communicable diseases, and injuries are also associated with educational attainment. In 1995 the death rate for men with chronic diseases who had less than 12 years of education was 2.5 times that of men with chronic diseases who had more than 12 years of education. The comparable ratio among women was 2.1.[77]

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[64] HHS, *Report of the Secretary's Task Force on Black and Minority Health*, vol. I, executive summary, August 1985, pp. 1–2.

[65] Geiger, "Race and Health Care," pp. 815–16.

[66] Erica Goode, "For Good Health, It Helps to be Rich and Important," *New York Times*, June 1, 1999, section F, p. 1.

[67] HRSA, *Health Status of Minorities*, pp. 11–13.

[68] Gregory Pappas et al., "The Increasing Disparity in Mortality Between Socioeconomic Groups in the United States, 1960 and 1986," *New England Journal of Medicine*, vol. 329 (July 8, 1993), pp. 103–09. Socioeconomic differences in health status are discussed further below.

[69] HHS, *Healthy People 2010 Objectives*, Goals, p. 20.

[70] *Health, U.S., 1998*, pp. 25–31.

[71] HRSA, *Health Status of Minorities*, p. 13.

[72] NCHS, *Health, U.S., 1998*, p. 145.

[73] HHS, "Asian Americans and Pacific Islanders: Action Agenda," accessed at <http://www.omhrc.gov/aamain.htm>. *See* Asian Americans and Pacific Islanders below.

[74] NCHS, *Health, U.S., 1998*, p. 30.

[75] Ibid., p. 149.

[76] Ibid.

[77] Ibid., p. 6.

Income

Education determines income, which also is strongly correlated to health status and access to health care. Data from the Bureau of the Census show that non-Hispanic whites and Asian Americans/Pacific Islanders, on average, earn more than blacks and Hispanics. The median household incomes for whites and Asian Americans/Pacific Islanders in 1997 were $40,577 and $45,259, respectively.[78] Comparatively, blacks earned a median household income of $25,050. The median household income for Hispanics was $26,628.[79] Although Asian Americans and Pacific Islanders as a group have higher median household incomes than other minority groups, their income-per-household-member estimate is lower than that of whites due to the larger size of Asian American and Pacific Islander households—3.17 people compared with 2.58 for white households.[80]

These disparities in median income, indicate that overall more blacks and Hispanics live in poverty than whites or Asian Americans. In 1996, 28 percent of blacks and 29 percent of Hispanics lived below the poverty level. Eleven percent of whites and 14.5 percent of Asian Americans/Pacific Islanders lived in poverty.[81] However, as with education, there is a great variation among poverty rates within racial/ethnic groups. For example, among Asian American groups, South East Asians have the highest poverty rates (Hmong 62.6 percent, Laotion 50.6 percent, Cambodian 47.3 percent) while Filipino and Japanese Americans have the lowest poverty rates (5.8 percent and 6.5 percent, respectively).[82]

Another indicator of economic status, besides median income, is asset holdings. Greater wealth allows a household to maintain its standard of living when income falls due to job loss or health problems.[83] Disparities in asset holdings between racial and ethnic groups exceed disparities in income. In 1993 the net worth of white households was 10 times that of black or Hispanic households.[84] These differences persist even among households with similar monthly incomes.

The ability to obtain health insurance coverage is directly related to income and wealth. For example, in 1994–95, low-income men were six to seven times more likely to be uninsured than high-income men, depending on race/ethnicity.[85] Further, children under 18 from low-income families often did not receive needed health care. Almost 20 percent of children from poor and near-poor families had no health insurance, whereas only 9 percent and 4 percent of middle- and high-income children, respectively, were uninsured.[86]

Income also is related to the amount of preventive care received, which is associated with health outcomes.[87] However, according to NCHS, "[t]he use of sick care, preventive care, and den-

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[78] U.S. Department of Commerce, Economics and Statistics Administration, Bureau of the Census, Current Population Reports, P60–200, *Money Income in the United States: 1997 (with Separate Data on Valuation of Noncash Benefits)*, September 1998, p. viii (hereafter cited as Census, *Money Income in the United States*).

[79] Ibid., p. viii. However, even within educational categories, income varies. According to NCHS:

> [I]ncome and education vary by race and ethnicity, but even within the same category of educational attainment, median family income varies by race and ethnicity and also gender. For men and women across all race and ethnic groups, the higher the level of education, the higher the median family income. However, within education level categories, men have higher median and family incomes than women, and median family incomes of Asian and Pacific Islander and white persons are higher than median family incomes of black or Hispanic men and women. Some of these differences, especially differences between men and women, may be attributed to the number of family members who are employed and to whether family members work full time or part time.

NCHS, *Health, U.S., 1998*, p. 30 (references to figures omitted).

[80] Census, *Money Income in the United States*, p. ix.

[81] NCHS, *Health, U.S., 1998*, p. 171.

[82] Ignatius Bau, Asian and Pacific American Health Forum, San Francisco, correspondence to Mireille Zieseniss, USCCR, March 1999 (re: information for health care project), enclosure, "Community Health Status Brief: Asian/Pacific Islander Community in California," p.1

[83] Council of Economic Advisers for the President's Initiative on Race, *Changing America: Indicators of Social and Economic Well-Being by Race and Hispanic Origin* (Washington, DC: September 1998), p. 34.

[84] Ibid.

[85] NCHS, *Health, U.S., 1998*, p. 7. In addition, Hispanic adults were less likely than non-Hispanic white and black adults to be insured. Ibid.

[86] Ibid., p. 5.

[87] For example, regular mammography screening has been shown to reduce the death rate due to breast cancer. Ibid., pp. 126–28.

tal care by adults varies with income."[88] High-income women 50 years of age and older are almost 70 percent more likely than poor women to have had a mammogram recently. Similarly, 77 percent of those with high family income have had a dental visit within the past 12 months, compared with only 41 percent of the poor.[89]

Occupation

There is an obvious relationship between income and occupation; therefore, type of occupation can have an effect not only on health care access (such as through insurance availability), but also on health status. Studies have shown that racial differences in risk of injury and illness are at least as great as racial differences in earnings.[90] Type of occupation also may affect health because of the exposure to health hazards and job-associated stress presented by certain occupations. For example, data from the Bureau of Labor Statistics show that, in 1996, in private industry, operators, fabricators, and laborers accounted for 42.4 percent of all occupational injuries resulting in days away from work. Service occupations; precision, craft, and repair occupations; and technical, sales and administrative support occupations each accounted for more than 15 percent of occupational injuries. Those in managerial and professional specialty occupations accounted for less than 6 percent of all occupational injuries, while those in farming, forestry, and fishing occupations accounted for less than 3 percent of all occupational injuries.[91]

Race and ethnicity are not evenly distributed across occupational categories; thus, exposure to occupational injury varies among groups. The issue of racial differences in exposure to the risk of work-related injury and illness is partially the result of the disjunction between equal employment opportunities and occupational health.[92] For example, of the relatively small number of injuries occurring in the agriculture, forestry, and fishing industries, 43.1 percent are suffered by Hispanics, while American Indians and Alaska Natives represent only 0.7 percent of occupational injuries in those industries. Whites, blacks, and Asian Americans/Pacific Islanders account for 39.1 percent, 3.9 percent, and 0.4 percent of the occupational injuries in that industry.[93] Similarly, blacks and Hispanics account for 9.1 percent and 10.4 percent of the occupational injuries in the finance, insurance, and real estate industries, while Asian Americans or Pacific Islanders account for only 2.2 percent of such injuries. Whites account for 49.3 percent of such injuries, and American Indians and Alaska Natives account for only 0.4 percent of such injuries.[94]

Environmental, Behavioral, and Biological Influences

Differences in income, education, and occupation alone do not explain all of the disparities in health status, as health is multidimensional. What other determinants can account for the fact that certain groups are affected differently by diseases such as HIV, heart disease, and cancer? There is no consensus on the answer to such questions, but there are several possible explanations. As suggested above, one answer is economic stratification. Because of socioeconomic disparities, there are class differences in access to health care and, thus, exposure to illness, disease, and injury. Others have suggested cultural reasons.[95] Factors such as social stress, diet, and physical activity, and genetic differences (such as metabolism and tolerance for certain drugs and diseases) also may be related to racial differences in health.[96] Speaking from a global perspective, one expert has stated:

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[88] Ibid., p.7.

[89] Ibid.

[90] James C. Robinson, "Trends in Racial Inequality and Exposure to Work-related Hazards, 1968–1986," *Milbank Quarterly*, vol. 65, suppl. 2 (1987), p. 404.

[91] U.S. Department of Labor, Bureau of Labor Statistics, "Table 2. Percent distribution of nonfatal occupational injuries and illnesses involving days away from work by selected workers characteristics and industry division, 1996," accessed at <http://stats.bls.gov/news.release/osh2.t02.htm> (hereafter cited as BLS, "Occupational Injuries").

[92] Robinson, "Trends in Racial Inequality," p. 404.

[93] BLS, "Occupational Injuries."

[94] Ibid.

[95] *See, e.g.*, Vernelia R. Randall, "Racist Health Care: Reforming an Unjust Health Care System to Meet the Needs of African-Americans," *Health Matrix*, vol. 3 (1993), p. 131 (stating "Factors affecting health include socioeconomic status, biology, and environment" which are all affected by race).

[96] Anthony P. Polednak, *Racial and Ethnic Differences in Disease* (New York: Oxford University Press, 1989), p. 285–87. The author notes that some researchers have found greater genetic homogeneity than differences among various

Racial/ethnic differences in infectious diseases are clearly due largely to factors subject to modification. These factors include nutritional deficiencies and poor host immune status, as well as poor sanitation and certain cultural practices. Population differences in infectious diseases such as hepatitis B include racial/ethnic variation in risk and modes of transmission, reflecting SES [socioeconomic status] and sociocultural differences.[97]

This author also stated:

Regarding the major chronic diseases, risk of hypertension, cerebrovascular diseases, and ischemic heart disease (IHD) varies considerably among countries and racial/ethnic groups, and these differences demand adequate explanation. In cardiovascular diseases differences in dietary habits affecting cholesterol fractions (high vs. low density) and sodium/potassium ratios, perhaps modulated by genetic differences that may themselves reflect past adaptations to diet, have emerged as most important. Population differences and time changes in smoking and alcohol habits are also important. This also holds for various cancers.[98]

As this author points out, several lifestyle behaviors can affect one's health, including cigarette smoking, heavy alcohol use, being overweight, and being sedentary.[99] For instance, according to NCHS:

Smoking is the leading cause of preventable death and disease in the United States. Smoking leads to an increased risk for heart disease, lung cancer, emphysema, and other respiratory diseases. Each year approximately 400,000 deaths in the United States are attributed to smoking and smoking results annually in more than $50 billion in direct medical costs.[100]

The prevalence of cigarette smoking is related to age, education, and income, and, thus, race, ethnicity, and gender. The percentage of persons smoking decreases as income increases.[101] Similarly, among both men and women, those with less than a high school education were almost twice as likely to smoke as those with a college degree or higher education.[102]

According to NCHS, the "[h]igher prevalence of cigarette smoking among those of lower socioeconomic status was manifested in elevated lung cancer and heart disease death rates for lower income adults during 1978–89."[103] As shown in table 2.2, in the poor, near-poor, and middle-income groups, Hispanic women are least likely to smoke cigarettes. Similarly, Hispanic males are less likely to smoke than all other groups, except Hispanic women. In the poor and near-poor income groups, white males and black males are the groups with the highest percentages of adults who smoke.[104] Thus, those persons are at greater risk for health problems.[105]

Table 2.2
Percentage of Adults 18 Years and Older Who Smoke Cigarettes by Race and Income, 1995

	Poor	Near poor	Middle income	High income
All races men	37.9	34.3	27.9	18.3
All races women	31.2	28.0	24.6	16.8
White men	42.3	37.5	24.6	–
White women	38.6	31.6	22.2	–
Black men	41.3	40.1	20.9	–
Black women	29.3	24.9	15.7	–
Hispanic men	26.3	19.7	16.3	–
Hispanic women	16.6	14.7	13.9	–

SOURCE: U.S. Department of Health and Human Services, National Center for Health Statistics, *Health, United States, 1998 with Socioeconomic Status and Health Chartbook*, 1998, p. 155. (Data not available for all groups in the high-income category.)

Another risk factor that varies by gender, race, and ethnicity is obesity. Overweight adults face an increased risk of hypertension, heart disease, diabetes, and certain cancers.[106] Between 1988 and 1994, the number of men and women who were overweight increased by 38 percent and 33 percent, respectively, placing more peo-

racial/ethnic groups. However, the author notes that further research is required and that differences in behaviors such as dietary habits, sexual and reproductive behaviors, stress, and migration "are important from an epidemiological perspective." Ibid., pp. 295–96. *See also* HRSA, *Health Status of Minorities*, pp. 44–48.

[97] Polednak, *Racial and Ethnic Differences*, pp. 285.

[98] Ibid., p. 286.

[99] NCHS, *Health, U.S., 1998*, pp. 108–23.

[100] Ibid., p. 108 (citations omitted).

[101] Ibid., p. 110.

[102] Ibid., p. 108.

[103] Ibid., p. 6.

[104] Ibid., p. 155.

[105] Ibid., p. 108.

[106] Ibid., p. 114.

ple at risk of developing certain health problems.[107] Further, minority women are more likely to be overweight than white women or men of all racial and ethnic groups. For example, the prevalence of obesity is 58 percent higher for black women than for black men.[108]

Because certain lifestyle behaviors, such as those mentioned above, can be correlated to health status, it can be argued that poor health may be partially attributed to personal choice. However, research indicates that, contrary to popular opinion, behavioral risks such as smoking and substance abuse account for only a modest portion of health disparities across age, sex, and race categories.[109] Further, not only does this viewpoint disregard the impact of uncontrollable influences, such as racism, on health status, but it fails to take into consideration the extent to which personal choice is limited by opportunities. In other words, poor nutrition and subsequent obesity are not always a matter of "choice" but rather a function of low income, the unavailability of nutritious foods, and lack of education about healthy diets. Rather than dismiss "risky" behaviors as elective, it is necessary to understand the complexities of social status that contribute to these unhealthy behaviors and to recognize possible cultural influences, particularly in the case of nutrition and diet. When personal responsibility is cited as the sole explanation for poor health status, factors that are not entirely within an individual's control can become a source of blame. As one scholar states:

> While the emphasis on personal responsibility for health and health behavior is desirable as a shift away from the established biomedical model of healthcare, it also has some inherent dangers. There is concern that, if taken to the extreme, it may result in "victim blaming" by attributing responsibility of individuals for health problems that are influenced by biological and contextual factors beyond their control.[110]

Further, attributing poor health status to a matter of choice merely serves to abdicate responsibility for the health of communities, particularly those of minorities and lower socioeconomic status individuals. The health care industry has a responsibility to understand and remedy unhealthy behavior to the extent that it disproportionately affect the health status of specific populations. Unless policymakers recognize that lifestyle behaviors are significantly influenced by the natural and social environment in which personal health decisionmaking occurs, their efforts to address the health care needs of *all* Americans will not be successful.[111]

This is not to suggest that individuals should not take responsibility for their own health. It is reasonable to expect individuals to assume some responsibility. Greater individual involvement in health care can increase the likelihood of positive health outcomes.[112] The President's Advisory Commission on Consumer Protection and Quality in the Health Care Industry advocates that individuals maximize healthy habits including exercise and diet; become more involved in specific health care decisions; and work toward carrying out agreed upon treatment plans.[113]

In addition to environmental and behavioral factors, biological differences also have been cited as an explanation for some of the gender and racial disparities in health. For example, it has been argued that racial differences in the incidence of hip fracture and osteoporosis can be attributed to racial differences in bone density, particularly at menopause, and in the production of certain hormones after menopause.[114]

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[107] Ibid.

[108] Ibid.

[109] Paula M. Lantz, James S. House, James M. Lepkowski, David R. Williams, Richard P. Mero, and Jieming Chen, "Socioeconomic Factors, Health Behaviors, and Mortality," *Journal of the American Medical Association*, vol. 279, no. 21 (June 3, 1998), pp. 1703–46. These authors found that while behavioral factors do affect health, they are not the primary mechanisms linking socioeconomic status and mortality. They conclude that public health policies and interventions that focus exclusively on individual risk behaviors have limited potential for reducing socioeconomic disparities in mortality. Ibid., p. 1707.

[110] Susan Nicole Walker, "Health Promotion and Prevention of Disease and Disability Among Older Adults: Who Is Responsible? Preventive Healthcare and Health Promotion for Older Adults," *American Society on Aging Generations*, vol. 18, no. 1 (Mar. 22, 1994), p. 45.

[111] Ibid.

[112] President's Advisory Commission on Consumer Protection and Quality in the Health Care Industry, "Consumer Bill of Rights and Responsibilities, Executive Summary," accessed at <http://www.hcqualitycommission.gov/final/append_a.html>.

[113] Ibid.

[114] Kenneth G. Manton and Eric Stallard, "Health and Disability Differences Among Racial and Ethnic Groups, in

One study found that African American women had higher levels of serum estrone and 23 to 27 percent higher bone mass, resulting in a relatively low occurrence of hip fracture.[115] These researchers also suggested that changes in vitamin D metabolism and absorption of calcium cause osteoporosis. However, blacks and whites have different sensitivity levels to vitamin D and parathyroid hormone, which may explain the lower incidence of osteoporosis for black women.[116]

Despite the many explanations for differences in health status, discrimination in health care delivery, financing, and research cannot be discounted as a major factor leading to disparities. According to one author:

> The delivery of health care in the United States is multitiered; the greatest levels of security and many of the benefits of medical research and advanced technology are reserved for selected segments of American society. Structural forms of racial discrimination and practices of segregation by providers of medical services are common and entrenched, and they ensure that such security and benefits are not available to many African Americans and most of the poor.[117]

Exploring Diversity and Confronting Disparities

"The term 'minority' falsely suggests a homogeneous groups of nonwhites. The reality is extraordinary diversity both within and among minority groups. . . ."[118]

"Growing ethnic diversity has placed new demands on the health care system to provide care that is culturally sensitive. Despite their practice locale, clinicians are increasingly likely to care for patients who have different values, beliefs, customs, and responses to illness than those of whites."[119]

The United States comprises more than 270 million people, all of whom have different health care needs and experiences. Disparities in health status, barriers to access, and discriminatory policies and practices have resulted in a national health care crisis for women and minorities.[120] Although several components of the U.S. Department of Health and Human Services, including the Office for Civil Rights, have attempted to address disparities in health care overall, relatively little attention has been paid to the different needs of minority subgroups. As a result, barriers to equal access to quality health care remain pervasive throughout the health care industry. HHS, and the Nation as a whole, must aggressively confront group-specific disparities and eradicate all forms of discrimination in the health care industry. Strong civil rights enforcement efforts are one element of this struggle.[121] Recognition of diversity within the United States, and within the Nation's racial and ethnic communities, is another necessary element. According to HHS:

> Many health programs are not designed with sensitivity to the diverse health beliefs, practices, use patterns, and attitudes of the many ethnic, cultural, gender, and age groups living in America today. In order to reduce health disparities and increase access to care for ethnic and cultural minorities and for the elderly in the United States, health programs must be culturally competent, age appropriate and gender specific.[122]

National Research Council, Linda G. Martin and Beth J. Soldo, eds., *Racial and Ethnic Differences in the Health of Older Americans* (Washington, DC: National Academy Press, 1997), p. 48.

[115] Ibid., p. 49, citing Cauley et al., "Black White Differences in Serum Sex Hormones and Bone Mineral Density," *American Journal of Epidemiology*, vol. 139, no. 10 (1993), pp.1035–46.

[116] Manton and Stallard, "Health and Disability Differences," p. 49.

[117] Marianne L. Engleman Lado, "Breaking the Barriers of Access to Health Care: A Discussion of the Role of Civil Rights Litigation and the Relationship Between Burdens of Proof and the Experience of Denial," *Brooklyn Law Review*, vol. 60 (spring 1994), p. 239.

[118] Herbert W. Nickens, "The Health Status of Minority Populations in the United States," *Western Journal of Medicine*, vol. 155, no. 1 (July 1991), pp. 27–32.

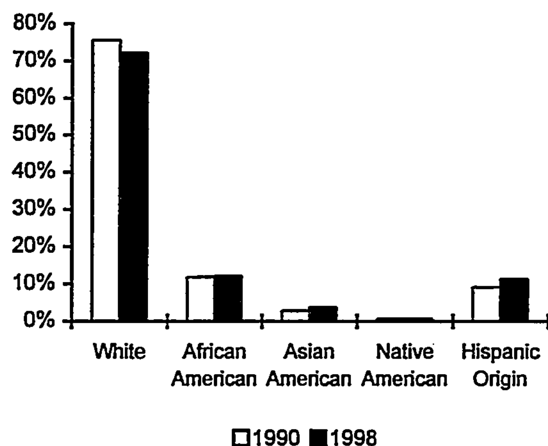
[119] Jeanette G. Kernicki, "A Multicultural Perspective of Cardiovascular Disease," *Journal of Cardiovascular Nursing*, vol. 11, no. 4 (July 1997), p. 31.

[120] *See also* chap. 3.

[121] *See* USCCR, *The Health Care Challenge*, vol. II in which the Commission provides several recommendations for improving the effectiveness of HHS' civil rights enforcement efforts.

[122] HHS, *Healthy People 2010 Objectives*, Educational and Community-Based Programs, p. 4–8.

Figure 2.3
Resident Population of the U.S., Percentage by Race and Hispanic Origin, 1990 and 1998



SOURCE: U.S. Department of Commerce, Bureau of the Census, "Resident Population of the United Stated: Estimates by Sex, Race, and Hispanic Origin, with Median Age," Dec. 28, 1998, accessed at <http:www.census.gov/population/estimates/nation/intfile3-1.txt>.

Federal, State, and local programs and initiatives aimed at addressing the health care needs of minority subgroups can not only assist in eliminating disparities, but they also can enhance and improve the effectiveness of OCR's civil rights enforcement. It is crucial that these two components, vigorous civil rights enforcement and coordinated program implementation, are both addressed if health disparities are to be eliminated for all Americans.

In this section, the Commission explores the diversity of the Nation's health status and the within-group differences among minority groups. Federal statistics agencies rely on four racial classifications, and one ethnic classification, to describe the population of the United States: white, black, Asian American/Pacific Islander, American Indian/Alaska Native, and Hispanic origin.[123] As shown in figure 2.3, white Americans, those of European descent, compose 72 percent of the Nation's population. African Americans are the largest minority group, representing 12 percent of the population. Asian Americans account for almost 4 percent of the population, while Native American groups represent just under 1 percent of the population. Persons of Hispanic origin, who can be in the "white" or "black" race categories, account for approximately 11 percent of the population.[124]

However, several commentators have suggested that analyzing only these five groups masks the intricacies of health status. For example:

> Cultural variations, combined with variations in SES [socioeconomic status] suggest that there will be considerable heterogeneity in the distribution of disease and risk factors for disease in racial or ethnic minority populations. . . . Failure to attend to the variations in health indicators within a racial category can prevent the identification of health needs for some specific groups.[125]

Thus, it is important to note the differences in health care status and access between whites and minorities, and men and women, as well as to take into account the heterogeneity of the minority groups themselves. Within each minority group, as well as among the white population, there exists broad diversity in both health status and use of health services which makes targeted examination of subgroups critical to understanding the needs of groups as a whole. Programs and initiatives must address these groups, while recognizing the unique circumstances and health care needs experienced by *all* members of the groups. All individuals developing Federal policies and designing civil rights enforcement strategies also must recognize these differences if health care disparities are to truly be eradicated.

[123] The Office of Management and Budget (OMB) controls the definition of race and ethnicity used for data collection in all Federal agencies, including HHS and its operating divisions, such as the Centers for Disease Control. For a more detailed discussion of racial and ethnic categories used by the Federal Government, *see* "Racial/Ethnic Categories in Federal Data Collection," below.

[124] U.S. Department of Commerce, Bureau of the Census, "Resident Population of the United States: Estimates, by Sex, Race, and Hispanic Origin, with Median Age," Dec. 28, 1998, accessed at <http://www.census.gov/population/estimates/nation/intfile3-1.txt>.

[125] David R. Williams, Risa Lavizzo-Mourey, and Reuben C. Warren, "The Concept of Race and Health Status in America," *Public Health Report*, vol. 109 (January/February 1994), pp. 26–41 (hereafter cited as Williams et al., "The Concept of Race and Health Status").

Profile of Five Communities

"Research dedicated to a better understanding of the relationships between health status and different racial and ethnic minority backgrounds will help us acquire new insights into eliminating the [health] disparities and develop new ways to apply our existing knowledge toward this goal. Improving access to quality health care will require working more closely with [all] communities to identify culturally-sensitive implementation strategies."[126]

An understanding of minority groups, and the characteristics of subcommunities within them, is crucial to recognizing the discriminatory barriers faced by many Americans in obtaining equal access to quality health care. It will be impossible to close the gap in health status between minorities and nonminorities unless subpopulations are closely examined. Looking at only the four racial/ethnic categories on a certain health risk behavior, such as substance abuse, reveals some differences by race/ethnicity, but does not reveal the entire story. As shown in table 2.3, breaking out data by race/ethnicity reveals differences in health risk factors among the minority groups, and also reveals dramatic differences among Hispanic subgroups. For example, Native Americans have a higher prevalence of cigarette, heavy alcohol, illicit drug, and marijuana use than any other racial/ethnic category. Further, marijuana use varies within the Hispanic community from 2.7 percent of Central Americans using marijuana in the past year, to 10.8 percent of Puerto Ricans.[127] Knowledge of these subtle differences is important when attempting to address health issues. Unfortunately, as shown by this example, data are not always broken down in this manner for other racial/ethnic categories.[128]

It also is important to examine the health experiences of these distinct groups apart from other groups, so that the issues specific to each group can be better understood. According to a report of the Washington State Department of Health, such an approach "avoids the suggestion of competition between groups that can arise from presenting side-by-side data (i.e., who is doing worst?)."[129] In addition, it may be useful in certain instances to compare one racial/ethnic group with "all others." For example, it can be useful to compare African Americans, for example, with all other groups, to focus on the specific disparities unique to those groups.[130] Such a comparison would show how a certain group fares compared to the rest of the country, thus highlighting significant disparities. Nonetheless, it is important that detailed data be collected on all racial and ethnic minority groups.

African Americans

"African Americans are at high risk for health problems, no matter what measures are used—birth risk factors, death rates, or sexually related conditions. Some of these problems may be related to socioeconomic factors, as reflected in higher African American use of social and health services and higher African American poverty rates. . . . The lack of data specific to African Americans has been cited as a major concern. . . ."[131]

African Americans experience health care differently from whites and other populations within the Nation. However, because of their long history in the United States and assumptions of homogeneity within the group,[132] there has been little research on diversity within the African American community. Further, while it may appear that data collected on minorities primarily focuses on African Americans,[133] data

[126] HHS, "Eliminating Racial and Ethnic Disparities," p. 2.

[127] HHS, Substance Abuse and Mental Health Services Administration, Office of Applied Studies, *Prevalence of Substance Use Among Racial/Ethnic Subgroups in the United States, 1991–1993,* April 1998, p. 49, table 4.1.

[128] *See* "Limitations of Racial/Ethnic Data" below.

[129] Washington State Department of Health, *Washington State Health Data Report on People of Color*, October 1992, p. 1 (hereafter cited as WA State Dept. of Health, *Data Report on People of Color).*

[130] *See, e.g.,* Missouri Department of Health; Division of Chronic Disease Prevention and Health Promotion; Office of Surveillance, Research and Evaluation, *Prevalence of Activity Limitation and Arthritis Among African Americans in the City of Saint Louis, Kansas City and the Bootheel Region of Missouri*, January 1999. In this study, African Americans were compared with whites/others together "because of the small number of 'other' ethnic/racial respondents and to highlight findings among African Americans." Ibid., p. 5.

[131] WA State Dept. of Health, *Data Report on People of Color*, p. 22.

[132] Nickens, "Health Status of Minority Populations."

[133] Ibid.

Table 2.3
Prevalence of Substance Use in the U.S. by Race/Ethnicity, 1991–1993

Race/Ethnicity	Cigarette use, past year	Heavy alcohol use, past month	Any illicit drug use, past year	Marijuana use, past year
Total U.S. Population	*30.9%*	*5.1%*	*11.9%*	*9.0%*
African Americans	29.9%	4.7%	13.1%	10.6%
Asian/Pacific Islanders	21.7%	0.9%	6.5%	4.7%
Caucasians	31.5%	5.3%	11.8%	8.9%
Hispanics				
Caribbean American	21.2%	2.5%	7.6%	5.6%
Central Americans	17.9%	2.2%	5.7%	2.7%
Cuban Americans	27.3%	2.8%	8.2%	5.9%
Mexican Americans	29.1%	6.9%	12.7%	9.1%
Puerto Ricans	32.7%	4.0%	13.3%	10.8%
South Americans	31.3%	3.0%	10.7%	8.4%
Other Hispanics	25.9%	4.9%	10.6%	9.1%
Native Americans	52.7%	4.6%	19.8%	15.0%

SOURCE: U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Office of Applied Studies, *Prevalence of Substance Use Among Racial/Ethnic Subgroups in the United States, 1991–1993,* April 1998, p. 49, table 4.1.

on the health status of African Americans are far from complete.[134] In addition, although some initiatives have targeted African American culture, the health care industry and researchers have not articulated the cultural barriers African Americans routinely have to overcome. For example, a report of the Washington State Department of Health observed:

> Major concerns about African American health relate to disparities in health care and the responsiveness of the system to meet African American needs, combined with the disparities of African American health status at each stage of life. Another concern is the difficulty of getting disaggregated data for African Americans and the lack of data targeted to the needs of African Americans.[135]

African Americans as a group have been in North America for longer than most racial/ethnic minorities,[136] with the exception of Native Americans. As such, African Americans are considered to be a homogeneous group, with few cultural differences.[137] However, the category "black" or "African American" often is interpreted to include more recent immigrants from Egypt, Ghana, Nigeria, Haiti, Panama, Jamaica, Trinidad, Barbados, and other Caribbean nations.[138] Recent African refugees include persons from Ethiopia, Somalia, Sudan, and Liberia.[139] Thus, there is diversity in the national origins, cultures, religions, and languages within the African American and black populations in the United States.[140] One author notes:

> [Individuals] now described as African American come from several specific cultural experiences that are different in terms of language, learned behavior, beliefs, and values. They come from the African con-

[134] *See* WA State Dept. of Health, *Data Report on People of Color*, p. 17.

[135] Ibid.

[136] *See* Nickens, "Health Status of Minority Populations," HHS, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services, *Cultural Competence Standards in Managed Mental Health Care for Four Underserved/Underrepresented Racial/Ethnic Groups*, Final Report from Working Groups on Cultural Competence in Managed Mental Health Care, prepublication copy, p. 2 (hereafter cited as SAMHSA, *Cultural Competence Standards*).

[137] Nickens, "Health Status of Minority Populations."

[138] SAMHSA, *Cultural Competence Standards*, p. 2.

[139] Clay Simpson, Deputy Assistant Secretary for Minority Health and director, Office of Minority Health, HHS, statement, "Healthy People 2000: Black American Progress Review," accessed at <http://www.cdc.gov/nchs/nchswww/about/otheract/hp2000/blkprog.htm>.

[140] Lorna Scott McBarnett, "African American Women," pp. 43–66 in Marcia Bayne-Smith, ed., *Race, Gender, and Health* (Thousand Oaks, CA: Sage Publications, 1996), p. 45; Williams et al., "The Concept of Race and Health Status."

tinent, from the English-, French-, Dutch-, Portuguese-, and Spanish-speaking nations of the Caribbean, and from the Americas, including the urban and rural areas of the United States. They mingle and live together in neighborhoods in the United States; because of their commonality of black skin and features, society regards them all as African Americans and aggregates their health and social problems as though they all share the same backgrounds, family structure, and belief systems. Unfortunately, this type of analysis, though relatively easy to do and report in the context of health policy and health status indicators, masks issues of cultural diversity, illness behavior, and preferences among these [individuals].[141]

Nonetheless, little research has been done and there is little information available on the relationship between health and culture for African Americans. One article in the *Journal of Cardiovascular Nursing* discussed the link between nature and healing by some African and Caribbean American persons. For example, the author noted that lemon juice, vinegar, and/or Epson salts are sometimes used as remedies for certain illnesses. In addition, root teas, herbal teas, and garlic tablets may be used to treat hypertension.[142] Further, according to the author, some African Americans may turn not to physicians but to other caregivers for health care advice, such as ministers in a church environment or older women in the community. This is in keeping with values focusing on family networks, religion, and reliance on traditional home remedies.[143]

According to the Centers for Disease Control (CDC), in 1996, 77,641 African Americans died from heart disease, the leading cause of death for blacks. Another 60,766 African Americans died from various cancers. The other eight most common causes of death for African Americans are cerebrovascular disease, human immunodeficiency virus (HIV), accidents, diabetes, homicide, pneumonia and influenza, chronic obstructive pulmonary diseases, and conditions originating in the perinatal period.[144] To effectively treat such health problems, and to reduce the disparities between African Americans and other racial/ethnic groups on such measures, it is important to recognize how culture can vary within the African American community, and how social factors are related to health.

For example, African American women in the District of Columbia have the highest death rates due to child birth in the country.[145] Almost 26 out of every 100,000 live births to black mothers in the District of Columbia result in maternal death, compared with a national rate of 19.6 deaths per 100,000 live births, which reflects the "dismal health status of African Americans in the District."[146] One reason may be the lack of prenatal care, which is compounded by African American women's distrust in the health care system. According to the *Washington Post*, many women "suffer so much social alienation that they simply withdraw and refuse to trust health care."[147] Such distrust may be the result of miscommunication, lack of culturally competent care, and discriminatory practices.

Cancer

In a recent telephone survey conducted for the New America Wellness Group and the Morehouse School of Medicine, 27 percent of African Americans identified cancer as the medical problem of greatest concern.[148] Compared with all other racial/ethnic groups, African Americans have the highest overall age-adjusted death rate for cancer.[149] According to HHS:

African Americans have a vastly different cancer experience from whites. Statistics show that African Americans have higher age-adjusted incidence and mortality rates for many cancers and lower survival rates that do whites for all but 6 of 25 primary cancer sites. This difference between the races represents both a challenge to understand the reasons, and an

141 McBarnett, "African American Women," p. 45.

142 Kernicki, "A Multicultural Perspective," p. 33.

143 Ibid., p. 34.

144 HHS, Centers for Disease Control, *National Vital Statistics Report*, vol. 47, no. 9 (Nov. 10, 1998), p. 33, table 8 (hereafter cited as CDC, *National Vital Statistics*).

145 Avram Goldstein, "Mothers' Childbirth Deaths Still High in D.C.: Rate for Black Women Reflects Racial Disparity," *Washington Post*, June 18, 1999, p. B–1.

146 Ibid., p. B–4. The national maternal mortality rate is 7.7 for all women, and 5.3 for white women. Ibid.

147 Ibid.

148 New America Wellness Group/Morehouse School of Medicine Multiethnic Healthcare Attitudinal Research, *Quantitative—Telephone Study, Hispanics/African-Americans/ Caucasians*, March 1999, p. 44 (hereafter cited as New America Wellness Group, *Telephone Study*).

149 NCHS, *Health, U.S., 1998*, p. 203. *See* app. 2.1.

opportunity to lower morbidity and mortality and to raise survival rates.[150]

In 1994 African American men had higher rates of prostate, lung, and oral cancer compared with other groups.[151] African American women had higher rates of cancer of the lung, colon, and rectum than other racial and ethnic groups, except Alaska Natives.[152] In 1996 the death rate due to breast cancer for African American women was 26.5 (per 100,000 people), compared with 19.8 for white women.[153] Although the incidence of breast cancer is somewhat lower for African American women compared with white women (100.5 cases per 100,000 and 112.8 cases per 100,000, respectively), African American women are more likely to develop breast cancer at younger ages, and are more likely to die as a result of breast cancer.[154]

There has been little research on health differences among the various African American populations. However, one study in the early 1980s found that, among English-speaking African Americans in the Northeastern United States, American-born black women had higher rates of breast cancer than Haitian and Caribbean immigrants. Further, both American-born and Haitian women had higher rates of cervical cancer than English-speaking Caribbean immigrants.[155]

Risk factors also vary among and within racial and ethnic categories. According to the American Cancer Society, risk factors related to cancer include being overweight and smoking. Approximately 28 percent of African American men and 38 percent of African American women are overweight. Further, 34 percent of African American men smoke, as do 22 percent of African American women.[156] Failure to take preventive measures also is related to high incidence rates of cancer. For example, only 55 percent of African American women over the age of 50 reported having had a mammogram and a clinical breast exam within the last 2 years.[157]

Diabetes

According to survey data, diabetes is another disease that African Americans are greatly concerned about—12 percent of the African American survey respondents identified diabetes as the medical problem of greatest concern to them.[158] One reason for this concern is that many African Americans have experienced diabetes through family members who have the disease.[159] Data from the Centers for Disease Control show that 2.3 million non-Hispanic blacks (10.8 percent) suffer from diabetes.[160] Further, 25 percent of African Americans between the ages of 65 and 74, and 25 percent of African American women over 55 have diabetes.[161]

Diabetes also is of concern because of the debilitating consequences it can have, including: heart disease, stroke, high blood pressure, blindness, kidney disease, amputations, and dental disease.[162] According to HHS' draft objectives for Healthy People 2010, "Diabetes is a major clinical *and* public health challenge, especially in minority communities where both the prevalence of diabetes and the risk of devastating associated complications is substantially

[150] HHS, *Healthy People 2010 Objectives*, Cancer, p. 17–5.

[151] American Cancer Society, "Cancer Facts & Figures—1997: Racial and Ethnic Patterns," accessed at <http://www.cancer.org/statistics/97cff/racial.html#group> (hereafter cited as American Cancer Society, "Racial and Ethnic Patterns").

[152] Ibid.

[153] NCHS, *Health, U.S., 1998*, p. 203. *See* app. 2.1.

[154] American Cancer Society, "Breast Cancer Facts & Figures 1997: Who Gets Breast Cancer?" accessed at <http://www.cancer.org/statistics/97bcff/who.html>.

[155] Williams et al., "The Concept of Race and Health Status," citing R.B. Hill, "Comparative Socioeconomic Profiles of Caribbean and non-Caribbean Blacks in the U.S.," paper presented at the International Conference on Immigration and the Changing Black Population in the United States, University of Michigan, Center for Afro American and African Studies, May 18–21, 1983.

[156] American Cancer Society, "Racial and Ethnic Patterns."

[157] Ibid.

[158] New America Wellness Group, *Telephone Study*, p. 44.

[159] Andrew Ehrlich, president, Ehrlich Transcultural Consultants, statement at New America Wellness Group Press Conference, Apr. 27, 1999, transcript, p. 9.

[160] HHS, Centers for Disease Control and Prevention, National Center for Chronic Disease Prevention and Health Promotion, National Diabetes fact sheet, Nov. 1, 1998, p. 2 (hereafter cited as CDC, Diabetes Fact Sheet).

[161] American Diabetes Association, African American Program, "Diabetes in African Americans," accessed at <http://www.diabetes.org/africanamerican/diabetesin.asp>.

[162] CDC, Diabetes Fact Sheet, pp. 3–4. *See also* Edward J. Sondik, director, National Center for Health Statistics, Office of Minority Health, HHS, statement, "Healthy People 2000: Black American Progress Review," accessed at <http://www.cdc.gov/nchs/nchswww/about/otheract/hp2000/blkprog.htm>.

greater than in the majority community."[163] The National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) also notes that the complications of diabetes disproportionately affect minorities. African Americans, for example, have higher rates of kidney failure and amputations resulting from diabetes than do whites.[164] In addition, African Americans are 40 to 50 percent more likely than whites to develop diabetic retinopathy.[165]

To increase awareness of diabetes within the African American community, the American Diabetes Association's African American Program has partnered with churches. According to the association:

> [Churches] provide an excellent setting for grassroots diabetes awareness programs. Churches have always played a critical role in the African American community. They provide strong community leadership, they have a genuine concern about the health of their members, and they can serve as a link between church members and the general community.[166]

Programs such as these will help increase awareness of diabetes and, it is hoped, assist in eliminating disparities in the prevalence of diabetes among racial and ethnic groups. Nonetheless, it is important to address the extent of civil rights violations that may contribute to differences in identification and treatment of diabetes.

HIV/AIDS

According to a survey by the Kaiser Family Foundation, more than one half of African Americans identified AIDS as the most urgent health problem facing the Nation.[167] The prevalence of HIV/AIDS is critical among minority populations in general, but particularly so among African Americans in the United States. African Americans and Hispanics exhibit rates of infection at approximately three times that of whites.[168] AIDS is the fourth leading cause of death among African American men and women combined.[169] Tragically, the number of those infected continues to grow, as AIDS cases in the black community multiply. In 1995, for every 100,000 African Americans, there were 92.6 reported cases of AIDS, a rate 6 times higher than that for whites and two times that for Hispanics.[170] African American men account for 39 percent of all new AIDS cases among men; African American women account for 60 percent of all new cases among women.[171] AIDS is the number one cause of death for African American men and women 25 to 44 years old.[172]

A large proportion of African American women of childbearing age also have AIDS. Studies show that HIV in African American childbearing women is 15 times that of white women.[173] This has the potential to result in a dramatic increase in the rates of pediatric AIDS in African American communities, particularly if these cases go untreated.

There are identifiable disparities in the mortality rates among minorities infected with HIV due to the late identification of the disease and lack of health insurance to pay for expensive drug therapies. Inadequate recognition of risk, detection of infection, and referral for followup care are major issues for African Americans as a high risk population.[174] Lack of detection is caused in part by the stigmatization African Americans associate with infection, because of the inferred association with other high risk groups such as intravenous drug users and ho-

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[163] HHS, *Healthy People 2010 Objectives*, Diabetes, p. 18–4.

[164] Jean Oxendine, "Who Has Diabetes?" *Closing the Gap*, February/March 1999, p. 5.

[165] Ibid. Diabetic retinopathy is a condition in which blood vessels in the retina are damaged. "Keep Sight of Diabetic Eye Disease," *Closing the Gap*, February/March 1999, p. 13.

[166] American Diabetes Association, African American Program, "Diabetes Sunday," accessed at <http://www.diabetes.org/africanamerican/sunday.asp>.

[167] Kaiser Family Foundation, *National Survey of African Americans on HIV/AIDS*, accessed at <http://hivinsite.ucsf.edu/social/kaiser_family_found/2098.393b.html>.

[168] Nickens, "Health Status of Minority Populations."

[169] HHS, Office of Minority Health Resource Center, "African American Health Facts," fact sheet, April 1997 (hereafter cited as OMHRC, "African American Health Facts").

[170] Ibid.

[171] Kaiser Family Foundation, *Survey of African Americans on HIV/AIDS*.

[172] OMHRC, "African American Health Facts." *See also* HHS, *Healthy People 2010 Objectives*, HIV, p. 21–4.

[173] WA State Dept. of Health, *Data Report on People of Color*, p. 22.

[174] HHS, "Eliminating Racial and Ethnic Disparities in Health."

mosexual men.[175] As a result, approximately one-third of blacks who are at risk have never been tested.[176] Better prevention strategies, which have a community specific approach, are necessary if the AIDS epidemic is to be controlled and the growth in infection rates curtailed.

Asian Americans and Pacific Islanders

"During our 160-year history, most portrayals of Asian Americans have perpetuated insidious stereotypes including the Eurocentric perception of Asian Americans as foreign, exotic, and non-American. There have been few images that reflect the complexity of Asian American experiences."[177]

"In order to provide adequate health services to all Americans, health researchers must incorporate knowledge of the great diversity of Americans into our health services."[178]

Demographic Profile

In 1997 the Asian American and Pacific Islander (AAPI) population in the United States was estimated at 10.1 million people, which is 3.8 percent of the total population.[179] By the year 2000, this population is expected to reach 12.1 million and represent about 4.0 percent of the total population.[180] Asian Americans and Pacific Islanders are not a homogeneous group. Subgroups differ in language, culture, and recency of immigration. Asian immigrants in the United States come from more than 30 countries and speak more than 100 different languages. In 1990 the largest subpopulations were Chinese, Filipino, Japanese, Asian Indian, Korean, and Southeast Asian. By the year 2000, Filipinos are projected to be the largest Asian subpopulation followed by Chinese, Vietnamese, Korean, and Japanese Americans.[181] (For a projected population comparison with other racial and ethnic minorities, see appendix 2.3).

Asian Americans and Pacific Islanders had a higher rate of population growth between 1990 and 1998 than any other race or ethnic group at 37 percent.[182] The AAPI population is young, with an estimated median age of 31.2 years—4 years younger than the median for the U.S. population as a whole. The largest percentage of Asian Americans and Pacific Islanders reside in the Western United States (55.7 percent).[183] The States with the highest concentration of AAPIs were Hawaii (63 percent of the total population), California (12 percent), Washington (6 percent), and New York and New Jersey (5 percent each).[184] In 1997, 24 percent of the Nation's foreign-born residents were Asian Americans and Pacific Islanders. Six in 10 AAPIs in the United States were foreign born.[185] China (including Hong Kong) and the Philippines were the leading countries of origin, after Mexico, for the Nation's foreign-born residents in 1997.[186]

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175 HHS, Office of Public Health and Science, Office of Minority Health, "The Minority AIDS Crisis," *Closing the Gap*, April 1999, p. 2

176 HHS, "Eliminating Racial and Ethnic Disparities in Health."

177 Maria Hong, ed., *Growing Up Asian American* (New York: Avon Books, 1993), p. 15.

178 Valentine M. Villa, Steven P. Wallace, Ailee Moon, and James E. Lubben, "A Comparative Analysis of Chronic Disease Prevalence Among Older Koreans and Non-Hispanic Whites; Vulnerable Populations, Part 2," Family and Community Health, vol. 20, no. 2 (July 1997), p.12 (hereafter cited as Villa et al., "Chronic Disease and Prevalence Among Older Koreans and Non-Hispanic Whites").

179 U.S. Department of Commerce, Census Bureau, Economics and Statistics Information, Bureau of the Census, Current Population Reports, "The Asian and Pacific Islander Population in the United States: March 1997 (Update)," accessed at <http://www.census.gov>.

180 U.S. Department of Commerce, Economics and Statistics Administration, Bureau of the Census, Statistical Brief, "The Nation's Asian and Pacific Islander Population—1994," accessed at <http://www.census.gov> (hereafter cited as Census, "The Nation's Asian and Pacific Islander Population—1994").

181 HHS, National Institutes of Health, Office of the Director, *Women of Color Health Data Book*, NIH Publication No. 98-4247, p. 16 (hereafter cited as NIH, *Women of Color Health Data Book*).

182 U.S. Department of Commerce, Economics and Statistics Administration, Bureau of the Census, "Census Bureau Facts for Features," accessed at <http://www.census.gov/Press-Release/www/1999/cb99ff06.html> (hereafter cited as Bureau of the Census, "Facts for Features").

183 U.S. Department of Commerce, Economics and Statistics Administration, Bureau of the Census, *Statistical Abstract of the United States, 1998*, October 1998, p. 31 (hereafter cited as Census, *Statistical Abstract, 1998*).

184 Census, "Facts for Features."

185 Ibid.

186 Ibid.

Often Asian Americans are considered to be a privileged and prosperous minority. While this is true for a few subgroups of Asian Americans, there are many who are economically disadvantaged. Although the median household income of Asian American and Pacific Islander families was $45,259 in 1997, approximately 14 percent of all AAPIs have income below the poverty level.[187] This is higher than the poverty rate for non-Hispanic whites and reflects the degree of disparity between subgroups. For example, Vietnamese Americans have an average family income that is about half that of the Asian American and Pacific Islander population as a whole.[188] Further, because AAPI households are, on average, larger than white households, their estimated income per member is lower ($18,569 compared with $20,093). Nationally, AAPI households have a median of 3.15 persons as compared with 2.23 in metropolitan white households.[189] AAPIs are more likely than non-Hispanic whites to reside in metropolitan areas (95 percent compared with 75 percent), and the proportion of AAPIs living in central cities is almost twice that of non-Hispanic whites.[190]

Educational attainment rates differ among the groups, with high school graduation rates varying from 31 percent for Hmongs to 88 percent for Japanese. Among Pacific Islanders the proportion with a high school diploma ranges from 64 percent for Tongans to 80 percent for Hawaiians.[191] In 1994, 46 percent of AAPI men and 37 percent of AAPI women held at least a bachelor's degree. Among the specific groups, Asian Indians had the highest proportion at 58 percent, and Tongans, Cambodians, Laotians, and Hmongs were the least likely to have a bachelor's degree with proportions of 6 percent or less.[192]

[187] Ibid.

[188] Nickens, "Health Status of Minority Populations," p. 27.

[189] U.S. Department of Commerce, Economics and Statistics Administration, Bureau of the Census, Statistical Brief, "Housing in Metropolitan Areas–Asian or Pacific Islander Households," accessed at <http://www.census.gov> (hereafter cited as Census, "Asian or Pacific Islander Households").

[190] Census, "The Nation's Asian and Pacific Islander Population—1994."

[191] Ibid.

[192] Ibid.

The Myth of the "Model Minority"

Some commentators contend that the "model minority" image surrounding Asian Americans was constructed to provide proof that the U.S. social system does work for minorities.[193] The "model minority" label has implications for the health and economic status of Asian Americans because their health problems are often ignored or trivialized, suggesting that they can take care of things on their own. Such a classification further overlooks the diversity among Asian Americans and some of the unique problems faced by recent refugees and immigrants.

By describing Asian Americans as socioeconomically and educationally successful, the "model minority" myth masks the needs of AAPI communities.[194] This claim of success is used as proof that racism does not cause disadvantage and, it has been argued, "The myth makes Asian Pacific Americans racial wedges to maintain white privilege against African Americans and Latinos. At the same time, that claim casts Asian Pacific Americans as honorary whites, denying both the racial identity of and the effects of racism on Asian Pacific Americans."[195]

When good health is assumed based on this myth of success, specific health problems may be overlooked.[196] It is ironic that the "positive" stereotypes of Asian Americans have such a negative effect and may be one reason for the lack of available health information. When stereotyping is positive, it can lead to hostility on the part of other minorities and the majority. It can further stifle assimilation by reinforcing public perceptions of the minority as "generic and unidimensional."[197] The image of Asian Americans as generally healthier than their white counterparts has been difficult to dispel.[198]

[193] NIH, *Women of Color Health Data Book*, p. 18.

[194] Lisa C. Ikemoto, "The Fuzzy Logic of Race and Gender in the Mismeasure of Asian American Women's Health Needs," *University of Cincinnati Law Review*, vol. 65 (spring 1997), p. 812.

[195] Ibid., p. 813.

[196] Ibid.

[197] Charles R. Taylor and Barbara B. Stern, "Asian-Americans: Television Advertising and the 'Model Minority' Stereotype," *Journal of Advertising*, vol. 26, no. 2 (June 22, 1997), p. 47.

[198] Ann Saphir, "Asian Americans and Cancer: Discarding the Myth of the Model Minority," Journal of the National Cancer Institute, vol. 89 (Nov. 5, 1997), pp. 1572–74.

Health Concerns

In 1992 the Commission reported that two factors appear to limit Asian Americans' access to health services in the United States: language and cultural barriers, and a lack of data depicting the health status of Asian Americans.[199] Seven years later, those barriers persist, compounded by cultural, linguistic, structural, and financial barriers to health care, particularly among specific groups of Asian Americans and Pacific Islanders.[200]

Differences in health status are a direct reflection of differences in ability to access health care services. One study showed that visits to the emergency room represent 18.8 percent of total visits to health care facilities by AAPIs as compared with 11.7 percent for whites.[201] If residing illegally in the United States, AAPIs may not seek out health care for fear that their residential status will be exposed and they will be deported.

Health insurance coverage also varies by subpopulation. Despite high rates of coverage in general, some subpopulations lack health insurance, which results in the inability to access health services and subsequently higher use of emergency room care. There are 2 million Asian Americans/Pacific Islanders without health insurance, with Korean Americans the most likely of any ethnic group to be uninsured.[202] Fifty percent of Korean Americans under the age of 65 living in Los Angeles have no health insurance.[203]

While there is relatively little information about specific within-group differences among the AAPI population, there is evidence that disparities exist, particularly for cardiovascular disease, cancer, and tuberculosis. There have been few studies done on cardiovascular disease in Asian Americans and Pacific Islanders. Of the few that are available on coronary heart disease, most focus on Japanese Americans. Those studies reveal that Japanese Americans have higher rates of coronary heart disease than do those living in Japan. The same is true for Filipinos, with higher rates for those living in the United States as compared with those in the Philippines.[204] Asians tend to have lower overall cholesterol levels and lower incidence of coronary heart disease than whites, but coronary heart disease is still the leading cause of death for all Asian Americans.[205] The risk of hypertension also varies by subpopulation, being more of a concern for Filipino Americans (25 percent) than for Chinese Americans (16 percent) or Japanese Americans (13 percent).[206] Not only do rates of cardiovascular disease differ, but the ways in which these illnesses are manifested and detected differ between racial and ethnic minorities, based on cultural beliefs and norms. According to one study:

> A belief in the Chinese culture is that the heart is the center of emotion. Thus, when Chinese Americans express strong emotion they frequently report cardiac symptoms. Careful screening of patients who complain of chest pain may help to delineate whether symptoms related to such emotional events as loss of a loved one are cardiac in origin or are manifestations of emotional upheaval.[207]

A major cardiovascular risk factor for Vietnamese males is cigarette smoking. When compared with other ethnic groups in the United States, Vietnamese males smoke at higher rates than white males and other Asian/Pacific males. Because so many Asian Americans and Pacific Islanders in the United States are immigrants, their lives have been influenced by a history of tobacco use in Asia and the Asian Pacific.[208] Smoking is prevalent among AAPIs in general, but rates vary according to ethnicity and gender. For example, among AAPI women, Japanese

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[199] USCCR, *Civil Rights Issues Facing Asian Americans in the 1990s* (Washington, DC: Government Printing Office, 1992) (hereafter cited as USCCR, *Civil Rights Issues Facing Asian Americans*).

[200] NIH, *Women of Color Health Data Book*, p. 18.

[201] Mayeno and Hirota, "Access to Health Care," p. 359.

[202] Bau, "We're Not All a Picture of Health," p. 5.

[203] NIH, *Women of Color Health Data Book*, p. 19.

[204] Kernicki, "A Multicultural Perspective," p. 34.

[205] Ibid.

[206] NIH, *Women of Color Health Data Book*, p. 19.

[207] Kernicki, "A Multicultural Perspective," p. 35.

[208] HHS, Centers for Disease Control and Prevention, National Center for Chronic Disease Prevention and Health Promotion, Office on Smoking and Health, *Tobacco Use Among U.S. Racial/Ethnic Minority Groups: A Report of the Surgeon General*, 1998, p. 211, accessed at <http://www.cdc.gov/tobacco/sgr-min-pdf/chap4.pdf> (hereafter cited as CDC, *Tobacco Use*).

American women are most likely to smoke and Chinese American women are the least likely.[209]

Tuberculosis (TB) is more common among Asian American populations than among any other racial/ethnic group, and is nearly four times that of the general population.[210] The incidence of TB is 41.6 per 100,000 among AAPIs, compared with 2.8 for whites, 22.4 for blacks, 16 for Hispanics, and 14.5 for American Indians/Alaska Natives.[211]

With the exception of Native Hawaiians, overall cancer rates among Asian Americans are lower than for whites. However, cancer killed more people than heart disease in only one racial or ethnic group in 1995: Asian American and Pacific Islander women. Cervical cancer is nearly five times more likely among Vietnamese American women than white women.[212] Liver cancer among Vietnamese Americans is more than 11 times higher than among whites. Chinese Americans have the highest rate of nasopharyngeal cancer of any racial/ethnic group.[213] Other prevalent types of cancer among AAPIs include hepatoma, lung, breast, gastric, and colon cancers.[214] Breast cancer incidence is lower among AAPIs than whites, but ranges from 29 cases per 100,000 among Korean women to 106 per 100,000 among Native Hawaiian women. Further, women whose families have lived in the United States longer are at greater risk than new immigrants.[215]

Compared with other racial/ethnic groups, Asian Americans and Pacific Islanders as a whole have relatively low rates of HIV/AIDS infection.[216] In 1996 Asian Americans reported 8 cases of AIDS per 100,000 people as compared with 111 cases among African Americans, and 52 among Hispanics.[217] In June 1997, the Centers for Disease Control and Prevention reported 4,370 known AIDS cases among AAPIs.[218] These low rates may reflect many factors, including differences in intravenous drug use and sexual behavior, but also the underreporting of infection.[219] AIDS outreach workers suggest that AIDS is vastly underreported among Asian Americans, partly because of a reluctance to discuss the sensitive topics surrounding AIDS. The result is that many Asian Americans do not seek medical attention until very late stages of the disease.[220]

The overall low rate of HIV infection has important implications for Asian Americans because it may result in a degree of complacency and lack of knowledge about the disease and high risk behaviors, despite recent growth in disease prevalence. The low numbers have also reinforced the denial of many Asian Americans that AIDS is indeed a threat.[221] Moreover, it has been speculated that because of the geographic and social isolation of many AAPI communities, the effect of HIV is magnified once it is introduced.[222]

Experts agree that education about the transmission of HIV is particularly important in populations where incidence rates are low because people may erroneously perceive themselves not to be at risk,[223] and because early education can be an effective prevention strategy.

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209 Ikemoto, "The Fuzzy Logic of Race and Gender," p. 814.

210 NIH, *Women of Color Health Data Book*, p. 20.

211 Ignatius Bau, "We're Not All a Picture of Health," Asian Week, The Voices of Asian Americans, Feb. 18, 1999, p. 5.

212 Ibid.

213 OMHRC, "AAPI Executive Summary."

214 Saphir, "Asian Americans and Cancer."

215 Ibid.

216 Although Asian Americans still exhibit low rates of AIDS, Asia faces the most rapidly growing epidemic of HIV in the world, with the number of Asians infected with HIV doubling between 1992 and 1996. In 1998 experts estimated that 7 million Asians are already infected with HIV. The World Health Organization speculates that if current trends continue, there may be more new HIV infections in Asia at the beginning of the 21st century than in either Africa or Latin America. *See* "Epidemiology AIDS Experts Say HIV is Gaining a Foothold in Asia," *AIDS Weekly Plus*, Dec. 14, 1998; and "Asia Expected to Have World's Highest Rate of HIV by Year 2000; World Health Organization Estimates," *AIDS Weekly*, May 4, 1994.

217 HHS, *Healthy People 2010 Objectives*, HIV, p. 21–10.

218 F.S. Sy, C.L. Chng, S.T. Choi, and F.Y. Wong, "Epidemiology of HIV and AIDS Among Asian and Pacific Islander Americans," *AIDS Education Preview*, vol. 10 (June 1998), pp. 4–18 (hereafter cited as Sy et al., "Epidemiology of HIV and AIDS").

219 Jenny K. Yi, "Vietnamese College Students' Knowledge and Attitudes Toward HIV/AIDS," *Journal of American College Health*, vol. 47, no. 1 (July 1998), pp. 37–42.

220 Somini Sengupta, "Making It Work: Asians Are Not Immune," *New York Times*, Jan. 3, 1996, section 13, p. 3.

221 Sy et al., "Epidemiology of HIV and AIDS."

222 Ibid.

223 Jennifer Tjia, "Cross-Cultural AIDS TeachingTeams Can Reach Diverse Asian Groups," *Public Health Report*, vol. 109 (March/April 1994), pp. 176–77.

According to one AIDS activist, "Other population groups were not given much time to perform outreach and primary prevention before the caseloads in their communities reached tragic peaks, but if we are effective as a community, we may succeed in thwarting a peak before it happens."[224]

However, efforts to educate Asian American and Pacific Islander communities appear to be lacking. According to an NCHS study that compares the health status of Asian American subgroups, Vietnamese Americans are more likely than any other group to report not knowing anything about AIDS (21 percent).[225] In addition, 9 out of 10 Vietnamese Americans and three-fourths of those in other Asian American subgroups have never been tested for HIV/AIDS.[226] A study by the San Francisco Health Department revealed that Chinese, Japanese, and Filipino Americans have a strong awareness of AIDS, but exhibit a "high level of ignorance" about how the disease is transmitted.[227]

There is also a degree of disparity in AIDS incidence rates among AAPI subgroups. For example, Filipino Americans have the highest percentage of AIDS cases among all Asian Americans and Pacific Islanders.[228] They account for 45 percent of all AIDS cases among Asians nationally. But, until recently, there has been little data collected on various Asian American ethnic groups, and yet State and Federal agencies have cited lack of statistics about AAPIs as a reason not to fund AIDS and HIV-related research and programs targeting Asian American communities.[229]

Underreporting, coupled with the failure of health agencies to collect data on HIV/AIDS in Asian American communities, contributes to the perceived low rates of occurrence. In 1994 the CDC mandated that all local and State health agencies perform community needs assessments and epidemiological profiles of their communities. Despite this mandate, many agencies have continued to fail to include Asian Americans and Pacific Islanders in their surveys and evaluations.[230] As a result, thorough data have not been collected on this population, particularly on the prevalence of AIDS. The Asian American and Pacific Islander population is also often misrepresented in the data that are available because AAPIs are categorized as "other" rather than a separate subgroup.[231]

Relatively little is known about other health concerns of specific Asian American populations, particularly those that have immigrated to the United States more recently. It has been argued that the data that are available have been used to make inferences about the health of all Asian American populations, but these conclusions are inadequate and exclude politically invisible minorities within the AAPI population, such as Koreans.[232] Translation of current available health data to include these subgroups is inaccurate, particularly due to socioeconomic differences and demographic diversity among Asian populations, as indicated above. This is especially true with older Asian Americans, since their cultural and immigration experiences differ greatly from those of younger Asian Americans and the generations of those who have been born in the United States:

> The need to tailor both the targeting of needs and interventions make it obvious that there is no single Asian formula that can work for the diversity of older Asians. The third-generation Japanese American, the Filipino World War II veteran who has been in the United States for 40 years, and the recently arrived older Korean will each have very different needs in addition to different cultures and experiences.[233]

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224 Valerie Chow Bush and Angelo Ragaza, "A Community Fights Back: Asians and AIDS," *Ethnic Newswatch*, vol. 1, no. 1 (Apr. 30, 1991), p. 16.

225 Sandra Smith, "First NCHS Study to Compare Health Status of Asian Groups," *Public Health Report*, vol. 113 (November/December 1998), pp. 557–58.

226 Ibid.

227 Elaine Herscher, "Asian Americans Uninformed About AIDS Virus, Survey Says," *San Francisco Chronicle*, Aug. 1, 1990, p. A–4.

228 Stacy Lavilla, "Filipino AIDS Summit Held in San Francisco: Health Advocates Call for Better Data," *AsianWeek*, vol. 19, no. 49 (Aug. 5, 1998), p. 13.

229 Wes Young, "A Positive Response," *Ethnic Newswatch*, Nov. 30, 1997, p. 22.

230 Asian Pacific Islander American Health Forum, fact sheet, "Asian and Pacific Islanders and HIV/AIDS," accessed at <http://www.apiahf.org/>.

231 Ibid.

232 Villa et al., "Chronic Disease and Prevalence Among Older Koreans and Non-Hispanic Whites," p. 1.

233 Ibid., p. 12.

The case of the growing Southeast Asian populations, including Vietnamese, Sino-Vietnamese, Cambodian, Lao, and Hmong, is unique as well. Many Southeast Asian refugees have severe health problems due to malnourishment, abuse, confinement and servitude in camps, and inadequate health care, particularly during war years.[234] Further, many have been forced to live in poverty-stricken and overcrowded conditions in the United States. Health problems that disproportionately affect these groups include tuberculosis, hepatitis B, malaria, malnutrition, conjunctivitis, trichinosis, anemia, leprosy, and intestinal parasites.[235] Approximately 40 percent of Southeast Asian refugees have encountered major difficulties in obtaining medical services.[236] Difficulties include lack of familiarity with the process of obtaining care, language problems, lack of financial resources to pay for care, and difficulties getting to health care facilities.

Pacific Islanders and Native Hawaiians make up only 5 percent of the total AAPI category and have somewhat different health concerns and thus different health needs than other Asian American groups. The needs of Native Hawaiians in particular are akin to those of Native Americans, as they share many health characteristics, including overall poorer health. For example:

- Compared with whites, Native Hawaiians experience excess death rates from heart disease, cancer, diabetes, infant mortality, and unintended injury.[237]
- Native Hawaiians are twice as likely as white residents of Hawaii to have diagnosed diabetes.[238]
- Native Hawaiians have the shortest life expectancy of any ethnic group in Hawaii, as well as the highest incidences of chronic diseases such as diabetes and heart disease of any ethnic group in the State.
- The age-adjusted death rate for Native Hawaiians is 901 per 100,000 persons, compared with 524 per 100,000 for the total U.S. population.[239]
- Nationally, Hawaiian males rank second only to African Americans in overall cancer death rates.[240]

Health experts in Hawaii have attributed the poor health status of Native Hawaiians to several factors, including poor diet and lack of exercise, failure to seek timely medical care because of conflicts in cultural values, and limited access to treatment by medical specialists.[241] Other Pacific Islanders also have some unique heath issues. For instance, in all the U.S.-associated Pacific Island jurisdictions, the rate of infant mortality exceeds that of the United States. Infant mortality rates range from 9.5 per 1,000 in Guam to 52 per 1,000 in the Federated States of Micronesia.[242]

Cultural Competency

Because of the great diversity among Asian American and Pacific Islander populations, one of the priority concerns for these communities is the need for culturally competent and culturally and linguistically appropriate health services.[243] Asians may avoid medical services that seem irrelevant to them; thus, for health care practitioners to provide culturally competent care, they must understand the importance of discussing health care issues and treatments with patients so that they understand why a particular action is necessary. For example, health care providers offering nutritional counseling to Asian Americans must be aware of the types of foods they generally eat.[244] Many times, the cultural beliefs of AAPIs are blamed for their un-

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234 Laura Uba, "Cultural Barriers to Health Care for Southeast Asian Refugees," *Public Health Report*, vol. 107 (September/October 1992), pp. 544–48.

235 Ibid., p. 544.

236 Ibid., p. 547.

237 Williams et al., "The Concept of Race and Health Status."

238 CDC, Diabetes Fact Sheet.

239 Bau, "We're Not All a Picture of Health."

240 Donne Dawson, "Healing Through Culture: Hawaiians Look to Heritage for Better Health," *Island Scene Online*, Oct. 7, 1998, accessed at <http://www.island scene.com/health/1998/981007/healing_culture/index.html>.

241 Ibid.

242 HHS, Office of Minority Health Resource Center, "Asian Americans and Pacific Islanders: Executive Summary," accessed at <http://www.omhrc.gov/overview2.htm> (hereafter cited as OMHRC, "AAPI Executive Summary").

243 Ibid.

244 Uba, "Cultural Barriers to Health Care for Southeast Asian Refugees," p. 547.

deruse of services; however, this perspective ignores the responsibility of health systems to respond to the multicultural changes in society.[245]

In Vietnamese culture, health is viewed as a facet of unity, harmony, and balance with the universe. Imbalance is believed to lead to discomfort and illness.[246] Dietary habits are also considered extremely important as demonstrated by the Vietnamese proverb, "Illness enters from the mouth."[247] When ill, many Vietnamese Americans will combine traditional cultural understandings of illness with Western medicine, which could lead to a divergence from prescribed treatments.[248] Vietnamese culture also idealizes stoicism, associating strength of character with the ability to withstand pain or discomfort. This belief may cause delay in seeking medical care until a disease is in an advanced state.

Despite their poor health conditions, there is evidence that Southeast Asian refugees underuse health services. Several cultural reasons have been cited for the lack of utilization of health services by Southeast Asians. One explanation may be a cultural attitude about the nature of life and the belief that suffering is inevitable.[249] As a result, medical treatment may be viewed as an inappropriate response to physical pain. For example, Hmong believe that the length of a person's life is predetermined, and therefore that life-saving health care is worthless.[250]

Another explanation for reluctance to use health services may be that Southeast Asian beliefs about sources of illness and treatment methods differ from Western models.[251] For instance, it is believed that illnesses are caused by a combination of organic problems and supernatural causes, such as an imbalance of the yin and yang, an obstruction of life energy, or failure to be in harmony with nature.[252] To remedy the resulting ailments, many rely on herbal remedies and religious healers. Since Western medicine only validates organic or psychological causes of illnesses, Southeast Asians may feel that it is inappropriate in many cases.[253] There is also a degree of mistrust toward medical providers, resulting in part from their inability to cure many illnesses due to the patient's delay in obtaining care. This distrust is further compounded by unfamiliarity with medical methods and diagnostic techniques:

> [M]any Southeast Asians misinterpret the functions of various diagnostic techniques. For example, some believe that X-rays are curative. If they undergo an X-ray procedure and do not become well, they may think that Western medicine is ineffective for their illness and not seek further Western medical services. Many Southeast Asian refugees believe that surgery upsets the soul or causes the spirit to leave the body. Some Lao, for example, believe that immunizing babies can be dangerous for the baby's spirit. Thus, they may balk at immunization, invasive diagnostic techniques, or surgery.[254]

The health care system has not yet responded to the growing and changing Asian American population by incorporating culturally sensitive health care delivery methods and adopting alternative approaches to health science. Many traditional culturally accepted medical treatments, such as acupuncture and herbal medicines, are not covered by health insurance plans, which further limits access to health care for those who subscribe to traditional Asian medical practices. Nearly all Cambodian women (96 percent), 18 percent of Laotian women, and 64 percent of Chinese women report using traditional health practices.[255] This reliance on non-Western health practices serves to deter Asian Americans from using westernized services, further disenfranchising their health needs. According to an NIH report:

> If Asian Americans get to health care providers and translators are available, communication still is not

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[245] Laurin Mayeno and Sherry M. Hirota, "Access to Health Care," pp. 347–75 in Nolan W. S. Zane, David T. Takeuchi and Kathleen N.J. Young, eds., *Confronting Critical Health Issues of Asian and Pacific Islander Americans* (Thousand Oaks, CA: Sage Publications), p. 355.

[246] Kernicki, "A Multicultural Perspective," p. 35.

[247] Ibid.

[248] Ibid.

[249] Uba, "Cultural Barriers to Health Care for Southeast Asian Refugees," p. 544.

[250] Ibid., p. 545.

[251] Ibid.

[252] Ibid.

[253] Ibid.

[254] Ibid., pp. 545–46.

[255] NIH, *Women of Color Health Data Book*, p. 20.

guaranteed and appropriate care may not be received. For example, differences between the medical systems in the United States and China constitute a further deterrent to Chinese Americans born in China but in need of health care in the United States. In China, physicians generally prescribe and dispense medication, charging only a nominal fee for their services; the major cost for the visit is the medications. Because the idea of a visit to a medical professional for a checkup without getting prescriptions for medications does not live up to the expectations of many Chinese Americans, they are reluctant to make visits for routine or preventive care. In addition, 90 percent of the obstetricians and gynecologists in China are female, a fact that makes it very difficult for foreign-born Chinese American women to be examined by or receive care from the predominantly male practitioners in these medical specialties in the United States.[256]

American women from certain Asian cultures may avoid seeking Western health care until something is seriously wrong because being examined by a male physician may be uncomfortable or even traumatic.[257]

Health care providers in the United States often lack understanding about the various Asian beliefs and cultures and thus are unable to provide adequate health care to these populations. However, it should be emphasized that the examples of cultural differences cited here do not necessarily apply to all Asian Americans, and, in their attempts to provide culturally competent health care, providers must be careful not to apply individual behaviors too broadly to entire groups. As one health care expert states, "Culture is dynamic and manifests constant change. Understanding another culture is a continuous and not a discrete process. It requires experience as well as study to grasp the many subtleties of another culture."[258]

Language Barriers

Of Asian Americans over 5 years old, 56 percent do not speak English "very well," and 35 percent are linguistically isolated.[259] However, locally based surveys suggest that English skills are even more limited than Census figures indicate.[260] Being unable to communicate symptoms and health concerns clearly can be frustrating. In addition, being unable to understand the physician's explanation of symptoms or treatments can be intimidating and can result in poor outcomes. Because there are relatively few health care providers who speak many Asian languages, translators are often relied upon. This can serve as a barrier to effective health care in itself if untrained translators embellish or minimize symptoms to the provider or unnecessarily frighten patients when conveying a diagnosis.[261] Frequently, translators are untrained family members or even children. Using children as translators presents unique issues; the parent-child relationship can reverse as the child becomes the mediator.[262] In addition, the child interpreter may lack comprehension, may not have sufficient vocabulary, or may not be mature enough to handle medical information.[263] Yet many patients accept this practice because they are not comfortable challenging the health care provider's authority.[264]

Even when translation services are made available, not all English medical terminology can be easily translated into the various Southeast Asian languages; likewise, many Southeast Asian expressions cannot be directly translated into English. Many Southeast Asian medical terms or health conditions when translated literally may mislead or confuse health care providers, resulting in inadequate or ineffective treatment.[265]

Poor communication between patient and physician can result from more than linguistic

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[256] Ibid., p. 21

[257] Kernicki, "A Multicultural Perspective," p. 35.

[258] Nathan Stinson, Acting Deputy Assistant Secretary for Minority Health, Office of Public Health and Science, HHS, letter to Frederick D. Isler, assistant staff director for Civil Rights Evaluation, USCCR, June 29, 1999 (re: comments on draft report) (hereafter cited as Stinson letter).

[259] U.S. Department of Commerce, Economics and Statistics Administration, Bureau of the Census, *We, the American Asians*, September 1993, p. 5.

[260] Mayeno and Hirota, "Access to Health Care."

[261] Uba, "Cultural Barriers to Health Care for Southeast Asian Refugees," p. 546.

[262] Francesca Gany and Heike Thiel De Bocanegra, "Overcoming Barriers to Improving the Health of Immigrant Women," *Journal of the American Medical Women's Association*, vol. 51, no. 4 (August/October 1996), p. 157.

[263] Ibid.

[264] Stinson letter, p. 3.

[265] USCCR, *Civil Rights Issues Facing Asian Americans*, p. 164.

differences. Southeast Asian styles of communicating emphasize respect for authority and politeness. Because of their respect for the health care provider as a person of authority, many Southeast Asians will not ask questions and will not voice reservations about techniques or treatment plans.[266] Communication may be worsened by insensitive behaviors. For example, crossing one's leg and letting one's foot point at the patient is insulting to some Southeast Asians.[267]

Hispanics

"Using risk factors associated with White middle class perceptions of health may eliminate important aspects of Hispanic illness and health care. For Hispanics it is crucial to recognize that the health care system may have less influence on health behavior than the family or the Church."[268]

"Latin Americans share many values and perspectives among themselves, stemming from the continuing powerful influence of their common Iberian heritage. . . . But each country has its own historical experiences which make it unique, and stereotyping 'Latin Americans' is not only wrong, it creates resentment. Latin Americans take great pride in their own country of origin and see themselves as Mexicans or Colombians, Chileans, Brazilians or whatever their nationality. They dislike being lumped together as 'Latin Americans.' (Hispanics in the United States are also highly heterogeneous and feel as strongly on this issue.)"[269]

The Hispanic American population is the second largest, and the fastest growing, minority group in the United States. In 1990 there were more than 20 million persons of Hispanic origin living in the United States, accounting for 9 percent of the total population. By 1995 that number had increased to more than 27 million, accounting for 10.4 percent of the U.S. population. It is projected that by the year 2050, Hispanics will account for 22 percent of the U.S. population.[270]

Table 2.4
Hispanic Population by Type of Origin, 1990

Origin	Percent
Mexican	61.2%
Puerto Rican	12.1%
Central American	6.0%
Cuban	4.8%
South American	4.7%
Spaniard	4.4%
Other Hispanic	3.9%
Dominican	2.4%

SOURCE: U.S. Department of Commerce, Economics and Statistics Administration, Bureau of the Census, *We the American . . . Hispanics*, September 1993, p. 4.

The Hispanic population is diverse by many measures, including ancestry, culture, and socioeconomic conditions.[271] As shown in table 2.4, in 1990 Mexican Americans accounted for the majority of Hispanics (61.2 percent), followed by Puerto Ricans who made up approximately 12 percent. Among Central Americans in the United States in 1990, 20.3 percent were Guatemalan, 15.3 percent were Nicaraguan, 9.9 percent were Honduran, 7.0 percent were Panamanian, and 4.3 percent were Costa Rican. Of South Americans, 36.6 percent were from Colombia, 18.5 percent were from Ecuador, and 16.9 percent were from Peru. Chileans and Argentineans accounted for 6.6 percent and 9.7 percent of South Americans in the United States, respectively.[272]

The diversity of countries of origin is magnified by differences in year of entry, immigration status, and English proficiency. Data from the 1990 census show that approximately 50 percent of the Hispanic population immigrated to the United States since 1980, yet this varies by

266 Uba, "Cultural Barriers to Health Care for Southeast Asian Refugees," p. 546.

267 Ibid.

268 WA State Dept. of Health, *Data Report on People of Color*, p. 69.

269 William A. Naughton, president, Inter-American Understanding, Inc., "Ten Mistakes to Avoid in Working with Latin Americans," cited in Bob Compton and Lonzo Kerr, *Accessing Services by the Hispanic Community* (Austin, TX: Texas Department of Health, Civil Rights Department), p. 30.

270 Census, *Statistical Abstract, 1998*, table 19. *See* app. 2.3.

271 U.S. General Accounting Office, *Hispanic Access to Health Care: Significant Gaps Exist* (Washington, DC: General Accounting Office, January 1992), p. 7 (hereafter cited as GAO, *Hispanic Access to Health Care*).

272 U.S. Department of Commerce, Economics and Statistics Administration, Bureau of the Census, *We the American . . . Hispanics*, September 1993, p. 4.

group. Among Mexican Americans, Dominicans, and South Americans in the U.S., approximately 30 percent immigrated to the United States during the 1970s, and almost 50 percent have arrived since 1980.[273] However, 46.3 percent of Cuban Americans arrived in the United States between 1960 and 1969; approximately 19 percent arrived in the 1970s, and another 26 percent have come to the country since 1980.[274] Central Americans are the most recent arrivals, with close to 70 percent having arrived in the United States since 1980.[275] In the 1980s, 47 percent of all immigrants to the United States were from Latin America.[276]

At the 1990 census count, Spanish was spoken by almost one-half of all non-English speakers in the United States, and almost half of persons of Hispanic origin stated that they did not speak English "very well." Seventy-eight percent of Hispanics spoke a language other than English at home.[277] English proficiency, however, varies by Hispanic subpopulation. Hispanic Americans with Spanish and Puerto Rican backgrounds have the highest English proficiency; 68.1 percent and 58.6 percent of those populations, respectively, reported speaking English "very well."[278] Only about one-third of Central Americans and Dominicans in the United States reported high English proficiency.[279]

Such within-group diversity also affects the way Hispanic subcommunities view and seek health care. For example, according to an NIH report, Hispanics with greater proficiency in English would be expected to have better access to health care services than recent Hispanic immigrants who, because of limited English proficiency, stronger ties with their homeland, and less familiarity with American tradition and culture, are less likely to understand and seek medical attention.[280] Further, although Hispanics share the same language, they do not necessarily share the same cultural, religious, and health beliefs and practices:

> [Hispanics'] cultural backgrounds are diverse, including Spanish, Aztec, Mayan, Incan, and Caribbean cultures, and Native American, White, and African American racial/ethnic origins. Their common language and link with Spanish culture serve as a means of considering them in unison, but their diverse religious, folk, family, and health beliefs and values as well as diverse linguistic idioms make them one of the most culturally rich groups in America.[281]

According to a report by the Washington State Department of Health, it is important to analyze the health concerns of Hispanics separately from other minority groups for several reasons. For example, several demographic factors unique to the Hispanic population affect their health needs, including: population growth rates in rural areas, low teenage abortion rates, large families, low birth weights, and low death rates.[282] These demographic considerations can also vary greatly among the various Hispanic subpopulations. However, according to one commentator:

> Few data are available on Hispanics in general, and the data [that] do exist tend to focus on the largest Hispanic subgroup, the Mexican American population. These data, however, do not address the problems of cultural, national, and lifestyle differences that may affect the health of other Latino populations. Nor do the data allow for differences in levels of acculturation, immigration history, or socioeconomic status, all of which have been shown to affect the rates and types of certain diseases, as well as patient

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[273] Ibid., p. 6.

[274] Ibid.

[275] Ibid.

[276] Ibid., p. 7.

[277] Ibid.

[278] Ibid.

[279] Ibid. In analyzing the impact of language on the health care of Hispanics, one study found that persons with limited English proficiency tended to be in poorer health, uninsured, and living in poverty. Those persons were less likely to have a regular source of health care services and, thus, less likely to have seen a physician or had their blood pressure checked recently. The researchers found that not speaking English was a barrier that affected the health care for members with limited English proficiency, regardless of the subgroup. Claudia L. Schur and Leigh Ann Albers, "Language, Sociodemographics and Health Care Use of Hispanic Adults, *Journal of Health Care for the Poor and Underserved,* vol. 7, no. 2 (1996), pp. 144–47, 156–57. *See also* Eliseo J. Perez-Stable, Anna Napoles-Springer, and Jose M. Miramontes, "The Effects of Ethnicity and Language on Medical Outcomes of Patients with Hypertension or Diabetes," *Medical Care,* vol. 25, no. 12 (1997), pp. 1212–19 (hereafter cited as Perez-Stable et al., "The Effects of Ethnicity and Language").

[280] NIH, *Women of Color Health Data Book,* p. 10.

[281] SAMHSA, *Cultural Competence Standards,* p. 7.

[282] WA State Dept. of Health, *Data Report on People of Color,* p. 75.

access to the health care system. Levels of education, literacy, assimilation, and socioeconomic status similarly reflect the diversity of the Hispanic population in the United States.[283]

The program coordinator for the Children's Health Initiative at the National Council of La Raza stated that the most prevalent health care issues and concerns of the Hispanic community are HIV/AIDS, teen pregnancy, diabetes, and the lack of research on the different Hispanic subgroups.[284] Several major issues that result in limited access to quality health care for the Hispanic population include: work demands, the type of work that does not provide health insurance, the lack of preventive care, immigration laws may dissuade undocumented immigrants from seeking medicaid or other government health aid, and the language barrier that limits access to services and information about medical terms and problems.[285]

Socioeconomic Issues

Although the Hispanic American population has grown steadily over the past decade, and members of the population now reside throughout the United States, the socioeconomic status of Hispanic Americans has not improved with their growth in numbers. In fact, the economic status of Hispanics has generally declined over the past 25 years.[286] This is due in part to the large numbers of immigrants who often have lower average levels of education and thus lower income.[287] In addition, lower rates of employment and labor force participation account for some of the high poverty level of Hispanics.[288] In 1995, 30 percent of the Hispanic American population had incomes below the poverty level.[289]

Location and living conditions of the Hispanic population also influence access to quality health care.[290] For example, 10 million Hispanic Americans, on both sides of the U.S.-Mexico border between California and Brownsville, Texas, live in areas lacking septic tanks, sewers, and running water.[291] Hispanics make up 75 percent of the farm workers in the country, and therefore are more likely to live in rural areas with fewer available medical services. The life expectancy for the farm worker population is 49 years; the infant mortality rate is 25 percent higher than the United States average; and the Hispanic rates of cancer and reproductive disorders within this group are higher than the general population.[292]

The high rate of poverty among Hispanics has compounded the difficulty many Hispanics face in accessing health care. A 1992 GAO report cites the lack of health insurance for Hispanic Americans as a primary barrier to accessing health care.[293] GAO looked at the issue in terms of employment, type of employer, and income, and concluded that Hispanic families were more likely to be uninsured than white or black families, even if there was an adult worker in the family; Hispanics were less likely than whites or blacks to be employed in industry that provides such coverage; and income levels of Hispanic males affected the rate of those Hispanics with insurance. The higher the income, the more likely the Hispanic male had insurance; the

[283] Aida L. Giachello, "Latino Women," pp. 121–71 in Marcia Bayne-Smith, ed., *Race, Gender, and Health* (Thousand Oaks, CA: Sage Publications, 1996), p. 129.

[284] Sonia Ruiz, program coordinator, Children's Health Initiative, Latin American Research and Service Agency (LARAZA), telephone interview, Mar. 9, 1999, p. 2 (hereafter cited as Ruiz Interview). LARAZA is a nonprofit organization established in 1968 with the objectives of reducing poverty and discrimination, and improving opportunities for Latinos in the U.S. Ibid.

[285] Ibid., pp. 2–3.

[286] Council of Economic Advisers for the President's Initiative on Race, *Changing America*, p. 2.

[287] Ibid.

[288] However, this also varies by subgroup. For example, unemployment rates for Mexican Americans and populations from Central and South America are near the Hispanic average, while rates for Puerto Ricans are above and rates for Cubans and other Hispanics are below this level. NIH, *Women of Color Health Data Book*, p. 9, citing to U.S. Department of Commerce, Bureau of the Census, *Statistical Tables for the Hispanic Origin Population from the March 1994 Current Population Survey* (Washington, DC: 1995).

[289] NIH, *Women of Color Health Data Book*, p. 9, citing to E. Baugher and L. Lamison-White, *Poverty in the United States: 1995*, Current Population Reports, Series P60–194, 1996.

[290] *See* Eli Ginzberg, "Access to Health Care for Hispanics," *Journal of the American Medical Association*, vol. 265, no. 2 (1991), p. 239.

[291] NIH, *Women of Color Health data Book*, p. 9. *See also* Ginzberg, "Access to Health Care for Hispanics," p. 239.

[292] NIH, *Women of Color Health Data Book*, p. 9.

[293] GAO, *Hispanic Access to Health Care*, pp. 9–10.

lower the income, the less likely the coverage.[294] The report also found that regardless of the three factors, Hispanic undocumented immigrants were less likely than other Hispanics to have insurance coverage.[295]

Another study describes the rates of health care access among a random sample of 501 Mexican Americans from San Antonio, Texas. Using a questionnaire, the researchers collected information on demographics, health status, health insurance coverage, and sources of health care.[296] Health care access was determined by having insurance coverage, as Mexican Americans, regardless of whether or not they were "poor," who had health insurance coverage had higher health care access rates.[297] Interestingly, more than one-third of the study population was uninsured; the women were overrepresented in the uninsured and public insurance groups; and those uninsured and public insurance participants had lower education and higher unemployment and poverty rates.[298] Although the study used a small sample, it confirmed the high rates of Mexican Americans from South Texas without health insurance coverage. The study shows that the uninsured Mexican Americans studied, who were mostly poor and less educated, were most in need of health care but also the least likely to receive it. The study also shows that when Mexican Americans have health insurance, they will use available services.[299] The researchers concluded that because high mortality from cancer and diabetes among minorities is assumed to reflect the effects of delayed medical care, it is important to increase their health care access rates through health insurance coverage. As the Hispanic population increases, young Mexican Americans will be a large part of the Nation's future workforce; therefore, health insurance and health care access will be imperative to improve the health status of this group.

While lack of insurance coverage is an important factor explaining the inability to access care for Hispanics, there are other factors that also contribute to lack of access, such as not having a usual source of care.[300] In addition to having high rates of uninsurance, Hispanic Americans are also substantially less likely than any other racial/ethnic group to have a usual source of health care.[301] One study found that the proportion of Hispanic Americans lacking a usual source of health care rose substantially during the period from 1977 to 1996—from 19.7 percent to 29.6 percent.[302] Thus, simply increasing health insurance coverage is not enough to eliminate inequalities in access to care.[303]

Other variables should also be addressed when assessing the barriers to health care faced by Hispanic Americans. According to one researcher, factors such as poverty, employment, language, and culturally competent care are "often neglected in the analyses of the health and health care access problems of Hispanic[s]."[304] For example, language barriers limit the choices of Hispanic women and their ability to acquire knowledge that enables them to have access to health care; cultural factors are disregarded in services and institutions that do not consider or recognize sociocultural differences in groups they serve, as a lack of understanding, myths and stereotypes, and prejudice prevail.[305]

Cultural Considerations

As with many other groups of racial and ethnic minorities, some Hispanics may share cultural beliefs that can have an effect on the provision of health services. For example, many His-

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294 Ibid., pp. 11–13.

295 Ibid., p. 10.

296 Robert P. Treviño, Fernando M. Treviño, Rolando Medina, Gilbert Ramirez, and Robert R. Ramirez, "Health Care Access Among Mexican Americans with Different Health Insurance Coverage," *Journal of Health Care for the Poor and Underserved,* vol. 7, no. 2 (1996), p. 112 (hereafter cited as Treviño, et al., "Health Care Access Among Mexican Americans").

297 Ibid., pp. 112, 116.

298 Ibid., p. 116.

299 Ibid., p. 120.

300 Samuel H. Zuvekas and Robin M. Weinick, "Changes in Access to Care, 1977–1996: The Role of Health Insurance," *HSR: Health Services Research,* part II, vol. 34, no. 1 (April 1999), p. 277. Having a "usual source of care" is defined as having regular access to the same provider or facility; this not only improves one's chances of receiving care when needed, but ensures consistency of care.

301 Ibid., p. 272.

302 Ibid., p. 275.

303 Ibid., p. 279.

304 Teresa C. Juarbe, "Access to Health Care for Hispanic Women: A Primary Health Care Perspective," *Nursing Outlook,* vol. 43 (1995), p. 24.

305 Ibid., p. 26.

panic Americans believe in the integration of physical, mental, and spiritual health. Those who subscribe to this theory believe that health exists when "the body, mind, and spirit are holistically balanced in relation to one's environment."[306] Some Hispanics may also incorporate traditional healing practices into their health regimens, such as the use of prayer, herbs, and folk remedies.[307]

One aspect of Hispanic culture that can affect the health status of Hispanics is the importance of family. Families provide a network of support, and Hispanics may rely more on relatives and friends for health services and advice than on health care professionals.[308] Another important institution is religion.[309] These two institutions, and traditional roles and values associated with each, may have an effect on access to health care and health-related activities. For example, it has been argued that "[t]raditional values inhibit the discussion of past sexual and drug history, areas that are critical as they relate to health education for women, early screening and treatment of women with sexually transmitted diseases, and women with dependency on alcohol and other drugs."[310]

Cultural influences on interpersonal relationships also affect the receipt of quality health care. For example, one Hispanic physician noted that Hispanic patients must feel comfortable that their doctors understand their culture. He stated:

> You go to an American doctor, it is very strange . . . the most he will do is shake hands with you. . . . You go to a Hispanic doctor and you see the patient, they come, they shake the hand of the doctor, they kiss the doctor, they hug . . . You go to an Hispanic doctor's office and every patient will bring cake, food, whatever. They see the doctor different. I mean, you never see that in an American doctor's office.[311]

In fact, survey results show that 61 percent of Hispanics believe it is very or somewhat important to have a doctor of the same ethnicity as themselves. However, only 40 percent of the Hispanic respondents said that they had a Hispanic physician.[312]

Diabetes

In a recent multicultural survey of health care attitudes, researchers found that diabetes was of great concern to Hispanics.[313] In the 1990s, diabetes in Hispanic Americans is a health challenge because of the greater incidence of the chronic illness that is found within this population, and the lack of early detection and treatment.[314] For example, about 5 percent of Hispanic Americans between the ages of 20 and 44 and 20 percent of those between the ages of 45 and 74 have diabetes.[315] Further, diabetes is two to three times more common in Mexican American and Puerto Rican adults than in non-Hispanic whites.[316] The prevalence of diabetes in Cuban Americans is lower, but still higher than among non-Hispanic whites.[317]

A 1998 Department of Health and Human Services fact sheet on diabetes reported that 1.2 million Mexican Americans, or 10.6 percent of all Mexican Americans, have diabetes and that they are 1.9 times as likely to have diabetes as non-Hispanic whites of similar age. Other Hispanic/Latino Americans, on average, are almost twice as likely as non-Hispanic whites of similar age to have diabetes.[318] More research needs to be done to explain the high rate of the disease in Hispanics, particularly in Mexican Americans.

HIV/AIDS

HIV/AIDS has become a major medical threat in the Latino community. In 1998, 20 percent of new AIDS cases were among Latinos even though Latinos account for only 11 percent of the total population. Approximately 110,000 to

306 Kernicki, "A Multicultural Perspective," p. 36.

307 Ibid.

308 Giachello, "Latino Women," p. 133.

309 Ibid., p. 134.

310 Ibid., p. 133.

311 Rene Rodriguez, president, Interamerican College of Physicians and Surgeons, statement at New America Wellness Group Press Conference, Apr. 27, 1999, transcript, pp. 16–17.

312 New America Wellness Group, *Telephone Study*, p. 14

313 Ibid., p. 44.

314 HHS, National Institutes of Health, National Diabetes Information Clearinghouse, "Diabetes in Hispanic Americans," accessed at <http://www.niddk.nih.gov/health /diabetes/pubs/hispan.htm#11> (hereafter cited as NIDDK, "Diabetes in Hispanic Americans").

315 Ibid., p.1.

316 Ibid., p. 2.

317 Ibid.

318 CDC, Diabetes Fact Sheet, p. 2.

170,000 Latinos are currently infected with HIV, an estimated 45,4000 of whom are living with AIDS.[319] In 1996 Latinos represented 17 percent of all cases among men and 20 percent of the total number of cases reported among women.[320] For Latino men, the AIDS case rate was nearly three times that for white non-Hispanic men (94.5 cases per 100,000, compared with 32.5 cases per 100,000), for women the rate was six times higher (23 cases per 100,000, compared with 3.8 cases per 100,000.[321]

Researchers studying the disease in the Latino community identified cultural factors that may impede members of this group from seeking medical care for HIV/AIDS. Issues such as perceptions of family responsibility and privacy, limited Spanish counseling and treatment services, lack of Spanish-speaking practitioners, and concepts of social relationships, may affect how members of the Hispanic community address the HIV/AIDS problem.[322] A 1993 study assessed AIDS prevention among non-Puerto Rican Hispanics, including Mexican Americans, Cuban Americans, and persons of Central and South American origin living in cities throughout the United States.[323] The report found a lower prevalence of HIV/AIDS among these groups, citing less usage of drugs and alcohol, and more cultural influence in their decisions, as reasons for the disparities in AIDS among the groups.[324]

Recent treatment advances and effective drug therapies have led to optimism about controlling the AIDS epidemic in the future, and there has been a decline in the mortality rate as many HIV-positive people are living longer. In 1996 Latino AIDS-related deaths declined by 20 percent, but for non-Hispanic whites, the rate declined by 32 percent.[325] Thus, Latinos continue to die from AIDS at a rate two and a half times that of non-Hispanic whites.[326]

These disparities in HIV/AIDS between Hispanic and non-Hispanic whites may reflect different access to health care services for members of this minority group. One report attributes the disparities to the lack of health insurance for a significant proportion of the Latino community and their inability to pay for HIV/AIDS treatment as major barriers to receiving health care for these diseases.[327]

Preventing the transmission of HIV is one of the objectives identified by HHS' Healthy People 2010 initiative. According to HHS:

> The disproportionate impact of HIV/AIDS on African Americans and Hispanics underscores the importance of implementing and sustaining effective prevention efforts for all communities of color. HIV prevention efforts must take into account not only the multiracial and multicultural nature of our society, but also other social and economic factors, such as poverty, underemployment, and poor access to the health care system, that impact health status and disproportionately affect African American, Hispanic, Asian/Pacific Islander, Alaska Native, and American Indian populations.[328]

Maternal and Child Health Care

There are "serious differences" in patterns of health service utilization among Cuban, Mexican, and Puerto Rican women.[329] Cuban and Puerto Rican women are more likely to receive preventive services than are Mexican women. These patterns of service utilization for Cuban and Puerto Rican women are attributed to the greater availability of health insurance. Cuban women are more likely to be covered by private medical insurance, and Puerto Rican women by medicaid.[330]

For Hispanic women, the most frequently used health care services are related to childbearing and reproductive roles. However, His-

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[319] *See* Kaiser Family Foundation, *National Survey of Latinos on HIV/AIDS*, accessed at <http://hivinsite.ucsf.edu/social/kaiser_family_found/2098.3a7e.html> (hereafter cited as Kaiser Family Foundation, *Survey of Latinos on HIV/AIDS*).

[320] Ibid.

[321] Ibid.

[322] Barbara V. Marin and Cynthia A. Gomez, "Latinos, HIV Disease, and Culture: Strategies for HIV Prevention," p. 9, accessed at <http://hivinsite.ucsf.edu/akb/1994/10-8/index.html>.

[323] Barbara V. Marin, "AIDS Prevention for Non-Puerto Rican Hispanics," NIDA, Monograph 93, "AIDS Intravenous Drug Use: Future Directions for Community-Based Prevention Research, accessed at <http://www.health.org/pubs/nida-m93/chapter3.htm>.

[324] Ibid., pp. 1–4.

[325] Kaiser Family Foundation, *Survey of Latinos in HIV/AIDS.*

[326] Ibid.

[327] Ibid.

[328] HHS, *Healthy People 2010 Objectives*, HIV, p. 21–8.

[329] Juarbe, "Access to Health Care for Hispanic Women," p. 24.

[330] Ibid.

panic women receive prenatal care only a third as frequently as white women, and their birth rate is 50 higher than that of white women.[331] To explain some of these rates, many Hispanic women who are "undocumented" tend not to receive prenatal care or are more likely to have waited until late pregnancy to seek medical attention. Newly arrived immigrants may be afraid of using the hospital or cannot afford the cost because they do not have medical insurance.[332]

Native Americans [333]

"We, the American Indians and Alaska Natives, are the original inhabitants of America. . . . Our long and proud heritage continues in our many traditional foods, medicines, and names all Americans use. We have survived numerous disruptions of our lives and dislocations from our native habitats. Today, while still maintaining our tribal traditions and languages, we strive to accept new technologies which address our needs."[334]

A fourth racial category identified by the Federal Government includes American Indians, Eskimos, and Aleuts. The 1990 census counted 437,079 American Indians, 192 Eskimos, and 97 Aleuts living in the United States on reservations and trust land.[335] However, not all Native Americans live on reservations and lands set aside by the Federal Government, or in rural areas. Among all three groups, approximately one-third of the members live on reservations, one-third live in urban areas, and another third "move back and forth between the two."[336]

A Washington State Department of Health report identifies two myths about Native Americans' health that are commonly heard. First, it is often assumed that the Indian Health Service (IHS) of the U.S. Department of Health and Human Services addresses the health care needs of all Native Americans.[337] IHS is the principal Federal "health care provider and health advocate for Indian people."[338] As such, it is estimated that close to 50 percent of the total Native American population is not served by IHS hospitals and clinics.[339] Further, IHS only provides services to enrolled members of federally recognized tribes and not all American Indians.[340] The second myth is that the Native American population is diminishing, thus rendering services for Native Americans unnecessary. However, since 1980 the Native American population has increased more than the general population, particularly in densely populated urban areas.[341] In addition to natural population increase (excess of births over deaths), there has also been a growth in the strength and prominence of Native

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[331] Ibid.

[332] *See* Ibid., p. 26.

[333] For the purpose of this report, the term Native American is used to include American Indians, Alaska Natives, Eskimos and Aleuts. The terms American Indian and Alaska Natives are used only when referring to those specific groups. Data presented here reflect the classification used in the various sources cited, however, it is often unclear whether the sources made the distinction between the classification of "Native American" and the various subgroups.

[334] U.S. Department of Commerce, Economics and Statistics Administration, Bureau of the Census, *We the . . . First Americans*, September 1993, p. 1 (hereafter cited as Census, *First Americans*).

[335] Census, *First Americans*, p. 1.

[336] NIH, *Women of Color Health Data Book*, pp. 1–2. *See also* David Satcher, Surgeon General, HHS, interview in Washington, DC, Apr. 30, 1999, p. 11. According to Dr. Satcher, when a Native American returns to a reservation, there is up to a 90-day waiting period before he or she is eligible for care through the IHS. Ibid.

[337] WA State Dept. of Health, *Data Report on People of Color*, p. 51.

[338] IHS, *Trends in Indian Health*, p. 1. The mission of the IHS is to provide "residual" health services to Native Americans and to assist Native Americans in accessing Federal, State, and local health care services. HHS, Public Health Service, Health Care Financing Administration, and OCR, Memorandum of Agreement, re: Provision of Medical Services to American Indians and Alaska Natives, March 1986, p. 1. However, IHS has developed "a health service delivery system designed to provide a broad spectrum of preventive, curative, rehabilitative, and environmental services" which "integrates health services delivered directly through IHS facilities, purchased by IHS through contractual agreements with providers in the private sector, and delivered through Tribally operated programs and urban Indian health programs." IHS, *Trends in Indian Health*, pp. 1–2.

[339] Les Hanson Lakota, "AIDS in the Native American Community: An Overview," *Ethnic News Watch*, July 1, 1994, p. 7. The Indian Health Service reported serving over 1.2 million American Indians and Alaska Natives in 1995, which is approximately 63 percent of the 1990 population of Native Americans. HHS, Indian Health Service, *Regional Differences in Indian* Health, 1996, p. 4.

[340] Stinson letter, p. 3.

[341] WA State Dept. of Health, *Data Report on People of Color*, p. 52.

American cultures due to changes in laws that permit the practice of cultural traditions.[342]

According to an NIH report, because of the cultural diversity among Native American groups, "it often becomes meaningless to classify them together for any but the most gross comparisons."[343] As such, it also is difficult to provide uniform, accessible, and quality health care for these groups.[344] Thus, it is important to recognize the diversity among Native Americans and to understand cultural differences.

Alaska Natives, Eskimos, and Aleuts

In 1990 there were 85,698 Alaska Natives living in Alaska. Among Alaska Natives, more than half are Eskimos. The two main Eskimo groups, characterized by the languages they speak, are the Inupiat, who live in the north and northwest parts of Alaska, and the Yupik, who live the south and southwest.[345] American Indians account for 36 percent of Alaska Natives. These individuals are members of the Alaskan Athabaskan, Tlingit, Tsimsian, and Haida tribes.[346] Twelve percent of Alaska Natives are Aleuts, who live primarily on the Aleutian Islands.[347]

There is relatively little information on the health of Alaska Natives, Eskimos, and Aleuts. Much of the research and information on Native American health is focused on American Indian populations, who face several obstacles to accessing quality health care. Many of these obstacles represent barriers to quality health care for other Native Americans, and other minorities, as well. Nonetheless, it is important for researchers and government agencies to recognize the health care needs unique to these communities.

American Indians

At last census count, there were 1,937,391 American Indians in the United States. According to the Census Bureau, the American Indian Tribes with the largest populations are the Cherokee, Navajo, Sioux, and Chippewa, all of which have more than 100,000 members (see table 2.5).[348]

California, Oklahoma, Arizona, New Mexico, Washington, Alaska, North Carolina, and Texas have the largest Native American populations.[349]

Table 2.5
Top 25 U.S. American Indian Tribes, 1990

Tribe	Number	Percent	Percent change 1980–90
Cherokee	369,035	19.0	31.0
Navajo	225,298	11.6	59.0
Sioux	107,321	5.5	42.0
Chippewa	105,988	5.5	36.5
Choctaw	86,231	4.5	44.0
Pueblo	55,330	2.9	71.7
Apache	53,330	2.8	30.0
Iroquois	52,557	2.7	48.7
Lumbee	50,888	2.6	37.5
Creek	45,872	2.4	77.7
Blackfoot	37,992	2.0	62.2
Canadian and Latin American	27,179	1.4	73.0
Chickasaw	21,522	1.1	248.0
Tohono O'Odham	16,876	0.9	108.6
Potawatomi	16,719	0.9	26.9
Seminole	15,564	0.8	72.1
Pima	15,074	0.8	50.2
Tlingit	14,417	0.7	28.6
Alaskan Athabaskans	14,198	0.7	51.6
Cheyenne	11,809	0.6	40.1
Comanche	11,437	0.6	26.6
Paiute	11,369	0.6	19.4
Osage	10,430	0.5	51.5
Puget Sound Salish	10,384	0.5	57.5
Yaqui	9,838	0.5	89.3
Total	1,396,658	72.1	

SOURCE: U.S. Department of Commerce, Bureau of the Census, "Table 1. Top 25 American Indian Tribes for the United States: 1990 and 1980," August 1995, accessed at <http://www.census.gov/population/socdemo/race/indian/ailang1.txt>.

[342] Ibid., p. 51.

[343] NIH, *Women of Color Health Data Book*, p. 2.

[344] Ibid., p. 1.

[345] Census, *First Americans*, p. 13.

[346] Ibid.

[347] Ibid.

[348] U.S. Department of Commerce, Bureau of the Census, "Table 1. Top 25 American Indian Tribes for the United States: 1990 and 1980," August 1995, accessed at <http://www.census.gov/population/socdemo/race/indian/ailang1.txt>.

[349] U.S. Department of Commerce, Bureau of the Census, "States ranked by American Indian population in 1997," Sept. 4, 1998, accessed at <http://www.census.gov/ population/estimates/state/rank/sori97.txt>.

There are 535 federally recognized tribes,[350] seven nations, and approximately 300 American Indian reservations. Further, there are more than 300 American Indian languages spoken in the United States.[351] A report of the Washington State Department of Health describes some of the issues concerning health care for American Indians:

> For some American Indians, geographic isolation, lack of transportation, and economic factors are barriers [to receiving quality health care]. For many, culturally rooted differences can pose significant barriers to accessing mainstream services. Important factors are language and communication styles, family values and structure, tribal lifestyles, and spiritual beliefs. Mainstream health services, which are predicated on dominant cultural assumptions, are often unacceptable to and sometimes ineffective for many Indian people. A high probability for misunderstanding and alienation occurs when mainstream providers are unfamiliar with tribal lifestyles, family values, or communication styles.[352]

There are several issues related to health status and equal access to quality health care for Native Americans. Among these are cultural differences within the Native American population, language barriers, traditional beliefs and practices, and differences between rural and urban Native American populations. Crowded living conditions, unchlorinated water, and inadequate sewage disposal systems contribute to the Native American's high rate of communicable gastrointestinal diseases.[353] Further, while the five leading causes of death for Native Americans as a whole are heart disease, cancer, accidents, diabetes, and chronic liver disease,[354] several health conditions deserve attention. This portion of the Commission's report touches on but a few of these issues.

Traditional Beliefs and Practices

One issue of concern to many Native Americans is cultural insensitivity and the lack of acceptance of traditional healing practices and traditional medicines. Some have argued that Native spirituality is often ignored or banned by health care practitioners. For example, traditional practices, such as alternative medicine, burning tobacco, and dream catchers, may be discouraged or belittled in a hospital setting.[355] Ultimately, this could have a long-lasting effect on the culture. According to an NIH report:

> Poverty has combined with the historical suppression of indigenous religions and medical practices to place American Indians/Alaska Natives at health risks due to environmental degradation. . . . The loss of traditional environments or ecosystems and the suppression of religions and medical practices threaten the body of knowledge developed from plants and herbs. As the environments supporting plant-derived compounds such as digitoxin and ephedrine are vanishing, the knowledge base among American Indians/Alaska Natives about the use of plants and herbs is vanishing even more rapidly.[356]

Traditional medicine has received little attention from researchers and medical practitioners, partly because of a lack of information concerning Native American, particularly American Indian, traditions. However, according to the Washington State Department of Health, "Within the broad scope of American Indian Religion, each tribe has its own belief system, rituals, and practices."[357] Religion and medicine are "inextricably linked"; and a priest or shaman is often the medicine man or woman. According to traditional beliefs, illness results from disharmony:

> Some of the core concepts held by many tribes include the belief of a Supreme Creator and in the universality of "spirit," which permeates all aspects of the world—animate and inanimate. Each person is viewed as a three-fold being of body, mind, and an

[350] An additional 100 tribes are not federally recognized. NIH, *Women of Color Health Data Book*, p. 1.

[351] Ibid.

[352] Washington State Department of Health, Office of Community and Rural Health, *American Indian Health Care Delivery Plan*, July 1997, p. 2 (hereafter cited as WA State Dept. of Health, *American Indian Health Care Delivery Plan*).

[353] WA State Dept. of Health, *American Indian Health Care Delivery Plan*, p. 1; NIH, *Women of Color Health Data Book*, p. 3.

[354] IHS, *Trends in Indian Health*, p. 62.

[355] Mark Anthony Rolo, "Native Americans with HIV/AIDS: The Invisible Victims; Native Community Develops Culture-Based Services," *Ethnic News Watch*, vol. 16, no. 11 (Nov. 30, 1995), p. 6 (hereafter cited as Rolo, "The Invisible Victims").

[356] NIH, *Women of Color Health Data Book*, p. 3.

[357] WA State Dept. of Health, *American Indian Health Care Delivery Plan*, p. 125.

immortal spirit. American Indians believe that wellness is harmony of body, mind, and spirit and that unwellness is disharmony that affects all three components.[358]

Traditional beliefs dictate that each individual is responsible for his or her own health and, as such, must play an active role in any illness recovery.[359]

Traditional healing practices include sweat lodges, ceremonial dances, singing, and prayer.[360] According to the Association of American Indian Physicians, alternative medicine, such as chiropractic services, hypnosis, biofeedback, and Native herbal therapy, should be available to Native Americans.[361] Those who practice traditional medicine and healing include healers, midwives, bone setters, and herbalists.[362] Commentators have argued that traditional healers are important in that they often are familiar with diseases common to their locality, are aware of changes in the common local diseases, and often are the first to treat such illnesses.[363]

A doctor practicing in Washington State provides an example of the importance of medical professionals working closely with Native American healers:

> [The doctor] and his traditional healer colleagues collaborate closely to discuss case histories, medicinals and treatments used, and to follow the progress of their mutual patients. This sharing of information is especially important to avert potential negative interactions between Western and traditional medicines and practices. For example, he reports the case of a diabetic patient who was taking Glyburide to lower blood glucose levels and who made three visits to the emergency room for severe hypoglycemia. After questioning her closely he learned that she was consulting a traditional healer and was participating in ceremonies that required her to drink 20 cups a day of an herbal tea made from devil's club, which has a potent hypoglycemic effect. He consulted with the traditional healer and learned that the ceremonies would last several more months, and so had his patient temporarily discontinue the Glyburide. "I knew it would be safe for my patient to go off this medication for awhile. In fact, the tea maintained good control of her blood sugar levels . . . ," he said.[364]

In addition, several IHS facilities permit traditional healers and medicine men and women to treat patients in those facilities.[365]

Another cultural practice that has an effect on health is tobacco use. According to the Surgeon General's report on tobacco, although attitudes about tobacco use have changed, some Native Americans have retained traditional practices surrounding tobacco. For example, in some American Indian communities tobacco is considered to be a medicine "that can improve health and assist in spiritual growth when used in a sacred and respectful manner."[366]

HIV/AIDS

Commentators have noted the unique problems experienced by Native Americans infected with HIV. One problem is that many tribes do not recognize AIDS as a serious health concern; another is that those infected fear that their confidentiality will not be protected in their small communities.[367] According to one writer:

> Many Natives who have been infected, or are at risk, are living outside their community. They are living on the dark edge of dominant society. They have been underserved by traditional Indian Health Services, and by the mainstream AIDS outreach community. They are an invisible Native population plagued by a disease that does not discriminate between creed, class or race.[368]

Another barrier to addressing HIV/AIDS in the Native American community is the lack of a cultural definition of the disease. For example, there is no word for HIV or AIDS in the Lakota

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[358] Ibid., pp. 125–26.

[359] Ibid.

[360] Ibid., p. 127.

[361] Ray Begay, president, Association of American Indian Physicians, "Unmet Health Care Needs of Native Americans," May 21, 1998, accessed at <http://www.aaip.com/policy/testimonay.html>.

[362] Nora Ellen Groce and Mary Elizabeth Reeve, "Traditional Healers and Global Surveillance Strategies for Emerging Diseases: Closing the Gap," accessed at <http://www.aaip.com/tradmed/cdc.html>.

[363] Ibid.

[364] WA State Dept. of Health, *American Indian Health Care Delivery Plan*, p. 129.

[365] NIH, *Women of Color Health Data Book*, p. 3.

[366] CDC, *Tobacco Use*, p. 210.

[367] Lakota, "AIDS in the Native American Community."

[368] Rolo, "The Invisible Victims."

language, and there are no traditional healing methods for the disease.[369]

A report of an HHS work group on health care access issues for American Indians and Alaska Natives noted that data on the extent of HIV/AIDS in the Native American population are limited. Such data are often based on the number of clinic attendees, which is then generalized to the larger population.[370] Thus, the work group argues, the percentage of Native Americans with HIV infection probably is underestimated.[371]

Diabetes

Diabetes is the fourth leading cause of death for Native Americans.[372] American Indians and Alaska Natives are twice as likely to have diabetes than the rest of the population: the 1996 Native American death rate due to diabetes was 27.8, compared with 7.3 for whites.[373] Over age 44, the death rate due to diabetes is higher for women than for men.[374] There are other within-group differences in diabetes rates. The Pima Indians of Arizona, for example, have the highest rate of diabetes in the world.[375] Half of the adult Pima Indians have type 2 diabetes.[376]

Mental Health

According to a report of the U.S. Department of Health and Human Services Substance Abuse and Mental Health Services Administration (SAMHSA), Native Americans are more likely to experience mental disorders than other racial and ethnic groups in the United States. "Of great concern is the high prevalence of depression, anxiety, substance abuse, violence, and suicide. Other common mental health problems of Native American individuals are psychosomatic symptoms and emotional problems resulting from disturbed interpersonal and family relationships."[377] According to SAMHSA, failure to address the "historic trauma" and culture of Native Americans in health care and other areas "will only add to the oppression experienced by Native Americans for decades."[378] Nonetheless, disentangling socioeconomic factors, cultural influences, civil rights issues, and the effect of race/ethnicity is difficult for any health condition, particularly mental health disorders. HHS cautions:

> Discussion of racial and ethnic differences in the prevalence of mental illness must be approached cautiously. Studies focusing on the prevalence rates among ethnic subgroups are limited and often inconclusive. Socioeconomic status, education, and employment status have been found to be related to the prevalence of mental disorders and explain some of the variance in the prevalence of mental illnesses across racial, ethnic, and economically diverse groups. It is difficult to determine the specific influence of social conditions such as discrimination and stereotyping on disorders with paranoid, depressive, and antisocial symptomology. However, low socioeconomic status and education, regardless of ethnicity, have been found to be contributing factors in the onset of certain disorders. Equally important, a discussion of prevalence rates must consider the cultural meaning of mental illness. Mental health behaviors need to be defined in the context of each individual's culture to determine normative behaviors.[379]

Women of Color

As has been demonstrated thus far, race/ethnicity and gender are two of several categories that can, to a large degree, determine

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[369] HHS, Public Health Service, Health Resources and Services Administration, American Indian Alaska Native Work Group on Barriers to HIV Care, *HIV/AIDS Work Group on Health Care Access Issues for American Indians/Alaska Natives*, DHHS Publication No. HRSA-RD-SP-93-6, 1992, p. 20 (hereafter cited as HRSA, *Health Care Access Issues for American Indians/Alaska Natives*).

[370] HRSA, *Health Care Access Issues for American Indians/Alaska Natives*, p. 18.

[371] Ibid.

[372] IHS, *Trends in Indian Health*, p. 62.

[373] NCHS, *Health, U.S., 1998*, pp. 96, 302. *See* app. 2.1.

[374] IHS, *Trends in Indian Health*, p. 119.

[375] Begay, "Unmet Health Care Needs."

[376] Oxendine, "Who Has Diabetes?" p. 5. Type 2 diabetes is non-insulin-dependent diabetes, which occurs during adulthood. Type 2 diabetes accounts for 90 to 95 percent of all diagnosed diabetes cases. CDC, Diabetes Fact Sheet, p. 3. Researchers at the National Institute of Diabetes and Digestive and Kidney Diseases have studied the nature of diabetes among the Pima Indians of Arizona since 1965, leading to several discoveries concerning the nature and treatment of diabetes. National Institute of Diabetes and Digestive and Kidney Diseases, National Institutes of Health, HHS, "The Pima Indians: Pathfinders for Health," accessed at <http://www.niddk.nih.gov/health/diabetes/pima/pathfind/pathfind.htm>.

[377] SAMHSA, *Cultural Competence Standards*, p. 11.

[378] Ibid., pp. 11–12.

[379] HHS, *Healthy People 2010 Objectives*, Mental Health and Mental Disorders, p. 23–4.

one's health. Groups occupying multiple social categories may have especially poor health status, such as poor women of color, since the effects of being among multiple disadvantaged groups can lead to cumulative vulnerability.[380] Women of color share the disadvantages of women *and* racial/ethnic minorities, thus their health concerns warrant further examination. Unfortunately, the current health system in the United States has failed to address the intersection of the many social factors as they affect health care and as a result has, to a large degree, ignored the unique yet pressing concerns of women of color. Minority women in the United States represent many diverse populations, however, collectively they use fewer health services and are in poorer health than white women.[381]

Who Are "Women of Color"?

Approximately 26 percent of the total female population are members of racial and ethnic minority groups.[382] Minority women are more likely than white women to have lower income levels and to live in poverty. They tend to have less education overall, but even when they have the same amount of education as white women, they tend to earn less and have fewer assets.[383] Many women of color have marginal jobs with little training, little security, and no possibility of advancement.[384] For example, many Puerto Rican and Asian American women work in the textile industry under sweatshop conditions; other minority women work as migrant farm workers under grueling conditions.[385] Further, studies have shown that households headed by women of color are at a particular disadvantage in the rental market, making obtaining decent housing difficult.[386] Poor health is connected to dangerous jobs and to marginal low-wage jobs. The inability to find good work, in turn, is related to poor education, which is related to segregated housing, which in turn affects health and then ability to work.[387] The cycle repeats itself. Therefore, health issues are only one thread in a complicated fabric of oppression.[388]

The "fabric of oppression" that is ingrained in the lives of women of color requires an understanding of how race/ethnicity-specific and gender-specific discriminations intersect to create a unique experience for women of color. These specific experiences have been neglected in part because of the failure to recognize them as more complex than the concerns of women or minorities when examined independently:

> The term "women of color" can be a helpful political tool. It is a phrase which is affirming and generous, a phrase which brings together a powerful coalition of women. However, there appears to be some uncertainty as to whether there is such a thing as a "true" women of color issue because these issues are often subsumed within the issues of others—white women, poor women, men of color.[389]

Often those issues of concern to women of color are categorized with issues of an entire minority community. Other times, issues of concern to poor women are collapsed with issues of concern to women of color. There is some confusion as to what women of color issues are. Are they the same issues faced by poor white women? Are they the same issues faced by minority men? One response is that women of color are faced with the problems of white women as well as those faced by minority men. For example, Hispanic and Asian American women deal with the issues of language and cultural differences just as their male counterparts must, but they also must deal with issues related to pregnancy and childbirth as do all women.[390] One commentator gives the example of a Latina who is pregnant. Her inability to get good prenatal care may be influenced by her status as an undocumented worker or by her lack of fluency with English. She faces difficulties because she is a woman and difficulties because she is part of the Hispanic community, which makes this a "women of

380 Williams et al., "The Concept of Race and Health Status."

381 HHS, Office of Public Health and Science, Office on Women's Health, "The Health of Minority Women," fact sheet (hereafter cited as OWH, "The Health of Minority Women").

382 OWH, "The Health of Minority Women."

383 Ibid.

384 Scales-Trent, "Women of Color and Health," pp. 1357–68.

385 Ibid., p. 1359.

386 Ibid., p. 1360.

387 Ibid., p. 1361.

388 Ibid., p. 1360.

389 Ibid., p. 1364.

390 Ibid., p. 1365.

color" issue.[391] Thus, when there is a greater impact or differential treatment from a general minority issue or women's issue, a women of color issue has been identified. In other words:

> A women of color issue can be located by looking at a woman's issue, or at an Asian or black or Indian or Latino issue, and by pushing further into that issue to locate the point where women of color look different—either because they suffer disproportionately or because they suffer differently.[392]

Specific Health Concerns

Barriers faced by minority women to health education, health promotion, preventive services, and medical care have resulted in disparities between minority and nonminority women in mortality and life expectancy, the extent and severity of illness, and the risk factors for developing major diseases.[393] As one commentator states:

> The health status of women of color in the United States has been determined to a large extent by the powerful abilities of race and gender to define as well as institutionalize who has access to resources, how much and what kind of resources are available to certain groups, and the manner in which those resources are provided. . . . In the area of health, more than in any other sphere of life, the structural restrictions of race and gender become linked to life and death.[394]

Unfortunately, however, women of color have traditionally been a low research priority, with relatively little data available on health issues specific to minority women. Even though there have been attempts made to improve the inclusion of women in research, this does not necessarily mean that there will be diversity among the women studied. Likewise, the inclusion of minorities in research trials does not guarantee that women will be among the various racial and ethnic subjects. Often, when studies look at race as well as gender, they look at either race or gender and not a combination of the two.[395] In addition, the inadequate or inaccurate data on minority populations, which is caused by small sample sizes, misclassification, and overgeneralized data collection, are major impediments to a full understanding of minority women's health status.[396]

The limited research that is available demonstrates that there are many health-related disparities between minority women and nonminority women. For instance:

- Asian American and Pacific Islander women have higher rates of death than white women for injuries and suicide.[397]
- American Indian/Alaska Native women have higher death rates for diabetes and chronic liver disease.[398]
- African American women have higher death rates than white women for heart disease, stroke, HIV/AIDS, homicide, and alcohol and drug induced causes.[399]
- Compared with white women, the death rate from HIV/AIDS for Cuban women is 2.4 times higher; for Mexican American women it is 5.4 times higher; and for Puerto Rican women it is 20 times higher. (More than 75 percent of women living with AIDS are women of color.)[400]
- Nearly half of all black women over the age of 60 have hypertension, and black women have 40 percent higher stroke rates than white women.[401]
- The incidence rate for uterine cancer for black women is twice that for white women, and black women have a higher mortality rate from breast cancer.[402]
- Black women are twice as likely to die from diabetes as white women, but Chinese American and Latina women face greater risk of developing diabetes during pregnancy than do black or white women.[403]

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[391] Ibid.

[392] Ibid., p. 1367.

[393] OWH, "The Health of Minority Women."

[394] Marcia Bayne-Smith, "Health and Women of Color: A Contextual Overview," p. 1 in Marcia Bayne-Smith, ed., *Race, Gender, and Health* (Thousand Oaks, CA: Sage Publications, 1996).

[395] Scales-Trent, "Women of Color and Health," p. 1364.

[396] OWH, "The Health of Minority Women."

[397] Ibid.

[398] Ibid.

[399] Ibid.

[400] Ibid.

[401] Scales-Trent, "Women of Color and Health," pp. 1361–62.

[402] Ibid.

[403] Ibid., p. 1362.

- Black women are three times more likely to die while pregnant than white women.[404]
- Alcoholism is a more prevalent problem for Native American women and Latinas.[405]
- Respiratory diseases are more common among Latinas. Puerto Rican women have the highest death rate due to pneumonia and influenza.[406]
- Ultimately, life expectancy is lower overall for minority women, including American Indian/Alaska Natives, Native Hawaiians, Hispanics (except for Puerto Ricans), and African Americans.[407]

One explanation for these disparities is the unavailability and inaccessibility of preventive health care services and, when services are available, differences in utilization patterns. For example, in 1991 sizable portions of all women 18 years and older reported that they had not had a Pap test within the past year. At that time, 37 percent of black women, 43 percent of Hispanic women, and 55 percent of Asian American women reported not having had a Pap test in the previous year.[408] These numbers have improved since 1991, but there are still disparities in use of preventive services among groups of women. A 1998 survey found that among African American women aged 50 and older, mammography rates increased from 37 percent in 1993 to 66 percent in 1998; for Hispanic women the rate of mammography increased from 54 to 64 percent.[409] However, Asian American women continue to have the lowest rates of preventive care; although the sample size of Asian American women over the age of 50 in the survey mentioned above was too small to estimate the percentage of these women who had had a mammogram, the survey indicates that less than half received a Pap test in 1998.[410] This is particularly disturbing considering the high rates of cervical and breast cancer among Asian American women. Hispanic women and Asian American women were also less likely than either white or African American women to have had a physical exam in the past year.[411]

Yet another pertinent health issue for women of color is violence. This is a major public health concern for all women, but specific attention needs to be given to the high rates at which violence affects minority women. African American women are three times more likely to experience violent crimes than white non-Hispanic women, and are much more likely to experience incidents of violence by acquaintances or strangers.[412] Although there is little data on domestic violence in the Asian community, women's shelters have revealed an overwhelming need for multicultural and multilingual counseling and advocacy services for Asian American women.[413]

These examples demonstrate the dire necessity to address the health needs of women of color. Researchers, health care providers, and advocacy groups must make a concerted effort to include minority women in their health care objectives. Health must become viewed as multidimensional, and as more than merely the absence of disease. The forces of race and gender clearly define the economic, social, environmental, and cultural components that shape health status.[414] The complexities of the health status of women of color require that health be redefined to include these factors, and that the health care system reassess the practices that cause minority women's health care needs to remain unmet. It has been stated that:

> Significant and sustainable improvement in the health status of women of color requires the development of new paradigms that expand or redefine concept of health in order to encompass many of the currently ignored essential elements of well-being. Good health status, as a product, is best defined as the re-

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404 Ibid., pp. 1361–62.

405 NIH, *Women of Color Health Data Book*, p. 41.

406 Ibid.

407 Ibid.

408 Ibid., p. 62.

409 The Commonwealth Fund, *Health Concerns Across A Woman's Lifespan; 1998 Survey of Women's Health*, (New York: The Commonwealth Fund, May 1999), p. 2.

410 Ibid., p. 40.

411 Ibid.

412 OWH, "The Health of Minority Women."

413 California Commission for Economic Development, Asian Pacific Islander Health Coalition, *California Asian Health Issues in the 1990s*, A Public Hearing, Apr. 20, 1990.

414 Bayne-Smith, "Health and Women of Color," p. 37.

sult of various kinds of investments in the total person. . . .[415]

Underreporting and Misclassification of Race

"Particularly lacking are data which recognize that concepts and measurements of health may differ within racial/ethnic groups and that traditional medical practices are often at odds with Western medical practice, making standard definitions of 'care' inappropriate."[416]

Racial/Ethnic Categories in Federal Data Collection

Currently, Federal agencies are required to collect data only on the following racial/ethnic groups:

- American Indian or Alaskan Native: "A person having origins in any of the original peoples of North America, and who maintains cultural identification through tribal affiliation or community recognition."
- Asian or Pacific Islander: "A person having origins in any of the original peoples of the Far East, Southeast Asia, the Indian subcontinent, or the Pacific Islands. This area includes, for example, China, India, Japan, Korea, the Philippine Islands, and Samoa."
- Black: "A person having origins in any of the black racial groups of Africa."
- Hispanic: "A person of Mexican, Puerto Rican, Cuban, Central or South American or other Spanish culture or origin, regardless of race."
- White: "A person having origins in any of the original peoples of Europe, North Africa, or the Middle East."[417]

New racial and ethnic categories will be used for the year 2000 census, and must be incorporated into new and revised reporting forms by January 2003.[418]

The revised racial and ethnic definitions have five categories. They divide the Asian or Pacific Islander category into two groups. A "Native Hawaiian or Other Pacific Islander" category includes any "person having origins in any of the original peoples of Hawaii, Guam, Samoa, or other Pacific Islands." It does not include individuals who are native to the State of Hawaii by virtue of being born there. The second category, "Asian," includes any "person having origins in any of the original peoples of the Far East, Southeast Asia, or the Indian subcontinent including, for example, Cambodia, China, India, Japan, Korea, Malaysia, Pakistan, the Philippine Islands, Thailand, and Vietnam." The other definitions remain much the same, although the "Hispanic" category is now designated as "Hispanic or Latino," and the "Black" category is now "Black or African American."[419] To accommodate persons of mixed racial heritage, another change permits respondents to select one or more racial designations.[420]

Misclassification of Race/Ethnicity

Proper classification of illnesses and assessment of health status require accurate data on members of certain populations. However, Native Americans, Asian Americans, and Hispanics, in particular, are often misclassified in surveys, censuses, vital statistics, and disease registries.[421] As noted by the Washington State Department of Health, difficulties identified with racial and ethnic data collection efforts include inconsistent definitions; misclassification of race and ethnicity, particularly on death certificates; lack of understanding of racial/ethnic categories by respondents; and changes to race/ethnic categories and responses over time.[422]

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[415] Marcia Bayne-Smith and Lorna Scott McBarnette, "Redefining Health in the 21st Century," pp. 173–74 in Marcia Bayne-Smith, ed., *Race, Gender, and Health* (Thousand Oaks, CA: Sage Publications, 1996).

[416] WA State Dept. of Health, *Data Report on People of Color*, p. 33.

[417] Office of Management and Budget, Statistical Policy Directive No. 15, "Race and Ethnic Standards for Federal Statistics and Administrative Reporting," 1977. *See* Joseph W. Duncan, director, Office of Federal Statistical Policy and Standards, U.S. Department of Commerce, *Statistical Policy Handbook*, May 1978, pp. 37–38.

[418] Office of Management and Budget, "Revisions to the Standards for the Classification of Federal Data on Race and Ethnicity," 62 Fed. Reg. 58,781–58,790 (1997).

[419] 62 Fed. Reg. 58,789 (1997).

[420] *Id.*

[421] WA State Dept. of Health, *American Indian Health Care Delivery Plan*, p. 93. *See also* IHS, *Trends in Indian Health*, p. 11.

[422] WA State Dept. of Health, *Data Report on People of Color*, p. 90.

In addition, there is often confusion over classification of individuals. For example, although Native Hawaiians are often placed in the Asian American/Pacific Islander category, in some circumstances this group can be considered Native Americans. For the purposes of title VIII of the Native American Programs Act,[423] for instance, Native Hawaiians, Somoans, and other native Pacific Islanders are considered to be Native Americans.[424]

Limitations of Racial/Ethnic Data

There are several limitations of existing data on race and ethnicity. A report by the Utah Department of Health for the University of Utah, Department of Health Promotion and Education, identified many of the difficulties in studying the health status of minorities:

> The great diversity in health needs and actions among people *within* each study population emerged as the greatest limitation on the breadth and depth to which we were able to examine health issues. Such factors as gender, age group, country of origin, documentation status, generational status or length of residence in the U.S., geographic location within [the State], level of family or community support, unmeasured psychological characteristics, health status, cultural factors and the varied availability of health insurance and health services within each population and sub-group made it impossible to simultaneously address all issues with all possible combinations of ethnicity and these other characteristics.[425]

In addition, using general racial/ethnic categories often masks the differences within a particular community.[426] For example, as discussed earlier, Asian Americans are often considered the "model minority"; however, when viewed in a group-specific context, variation is demonstrated. The erroneous assumption of homogeneity is compounded by lack of data:

> Common data sets combine all subgroups as 'Asian' or, even worse, combine all Asian Pacific Americans with 'Other Non-White', which minimizes Asian Pacific American health needs and reduces the possibility of identifying high-risk Asian Pacific American subgroups. Furthermore, national and statewide health and behavior surveys do not sample enough Asian Pacific Americans to provide meaningful estimates of health status, health care utilization, and risk factors.[427]

Similarly, the length of time a minority group has been in the United States can affect how they relate to medical practitioners and take care of their health. For example, among Asian Americans, three groups—Chinese, Japanese, and Filipino Americans—have the longest history in the United States and, thus, are more familiar with Western medical practice and lifestyle than other Asian American groups. Thus, it is "dangerous to generalize the findings from these groups to recent immigrants, most of whom are included in the 'Other Asian Pacific American' group, which is itself a large group with a diverse population."[428]

There is also a lack of disaggregated information on, and information targeted to the specific needs of, specific minority groups.[429] For example, there is little information on the differences between American Indians who live on reservations and those who live in urban areas. Because of the mobility between reservation and nonreservation areas, it often is difficult to collect data and provide services to many American Indians.[430] Similarly, because the classification "Hispanic" refers to the country of origin of a person or his or her ancestors, the Hispanic population comprises several ethnic, cultural, and racial groups, which further blurs the differences within the category.[431]

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[423] Pub. L. No. 88–452, title VIII, § 801, as added Pub. L. 93–644, § 11, Jan. 4, 1975, 88 Stat. 2323 (codified as amended at 42 U.S.C. §§ 2991–2992d (1994 and Supp. II 1996)).

[424] 42 U.S.C. § 2991a (1994). *See also* SAMHSA, *Cultural Competence Standards,* p. 9 (which classifies Native Hawaiians as Native Americans along with American Indians and Alaska Natives).

[425] University of Utah, Research and Evaluation Program, Department of Health Promotion and Education, *Final Report: Utah Health Status Survey on Ethnic Populations–Qualitative Component,* report prepared for Utah Department of Health, Bureau of Surveillance and Analysis and Statewide Ethnic and Health Committee, Nov. 24, 1997.

[426] NIH, *Women of Color Health Data Book,* p. 93.

[427] WA State Dept. of Health, *Data Report on People of Color,* p. 33.

[428] Ibid.

[429] Ibid., p. 17, 51.

[430] Ibid., p. 51; HRSA, *Health Care Access Issues for American Indians/Alaska Natives,* p. 18.

[431] WA State Dept. of Health, *Data Report on People of Color,* p. 69.

Although a discussion of the intricacies of collecting racial and ethnic data are beyond the scope of this report, it should be noted that several solutions to the problem of incomplete racial/ethnic data and insufficient samples have been suggested. In 1997 the Secretary of HHS issued the "HHS Policy for Improving Race and Ethnicity Data," thereby affirming the need for comprehensive data collection efforts throughout HHS.[432] The purpose of the policy is to emphasize the importance of the inclusion of data on minority groups in HHS research, to monitor HHS programs to ensure that funds are being used in a nondiscriminatory manner, and to promote the standardization of data collection across the Department.[433] This policy is consistent with policies already adopted by NIH and CDC regarding the inclusion of minorities in research.[434] However, one NIH report takes data collection one step further by recommending the oversampling of racial and ethnic groups in national surveys and/or surveying racial/ethnic subpopulations in the areas where they predominantly are found.[435] The report also recommends collecting information on immigration, language, and acculturation to fully understand the health status of different subpopulations.[436]

As one commentator stated:

> Additional data that capture the specific factors that contribute to group differences in disease must be collected. However, reductions in racial disparities in health will ultimately require change in the larger societal institutions and structures that determine exposure to pathogenic conditions. More attention needs to be given to the ways racism, in its multiple forms, affects health status. Socioeconomic status is a central determinant of health status, overlaps the concept of race, but is not equivalent to race. Inadequate attention has been given to the range of variation in social, cultural, and health characteristics within and between racial or ethnic populations. There is a growing emphasis, both within and without the Federal Government, on the collection of racial and ethnic identifiers in health data systems, but noncoverage of the Asian and Pacific Islander population, Native Americans, and subgroups of the Hispanic population is still a major problem. However, for all racial or ethnic subgroups, we need not only more data but better data. We must be more active in directly measuring the health-related aspects of belonging to these social categories.[437]

Despite the limitations of and difficulties in data collection, it is important to continue to strive to collect the most complete data on racial and ethnic minorities, and subpopulations. To the extent that national estimates are unavailable, community studies and local censuses are crucial to the understanding and elimination of health disparities. An absence of appropriate data should not be an excuse to continue to disregard the health needs of certain segments of society, and minorities as a whole.

Absence of Cultural Competency in Service Delivery

"The widening gap in healthcare between people of color and white America is not due solely to economics, but to the lack of culturally relevant healthcare treatment and medical information designed to reach the nation's fastest growing populations effectively."[438]

As demonstrated, both the delivery of and access to health care services are dependent on many factors. One issue of particular concern to racial and ethnic minorities, and which is often neglected, is the cultural competency with which health care services are rendered. Culturally competent care is defined as care that "is sensitive to issues related to culture, race, gender and sexual orientation. . . ."[439] According to HHS,

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[432] Donna E. Shalala, Secretary, HHS, memorandum to Heads of Operating Divisions and Heads of Staff Divisions, Oct. 24, 1997 (re: HHS Policy for Improving Race and Ethnicity Data).

[433] Ibid.

[434] For discussion on NIH and CDC inclusion policies, *see* chap. 3.

[435] NIH, *Women of Color Health Data Book*, p. 93. In sample surveys, based on the national population, the number of minorities in the sample is often too small to develop national estimates. Thus, it is necessary to "oversample" groups by, for example, increasing the sample size in areas where minorities live. *See* Ronald M. Andersen, Ross M. Mullner, and Llewellyn J. Cornelius, "Black-White Differences in Health Status: Methods or Substance?" *Milbank Quarterly*, vol. 65, suppl. 1 (1987), pp. 73–74.

[436] NIH, *Women of Color Health Data Book*, p. 93.

[437] Williams, et al., "The Concept of Race and Health Status."

[438] New America Wellness Group, "Economics Not Sole Reason for Healthcare Inequality Among Minorities," press release, Apr. 27, 1999, p. 1.

[439] Juarbe, "Access to Health Care for Hispanic Women," p. 26.

cultural competency involves ensuring that a system (e.g., agency, program, individual) can function effectively in a culturally diverse setting; it involves understanding and respect for cultural differences.[440]

In particular, cultural competency ensures that health care needs are identified and care is provided within the cultural context of the patient. A cultural group shares common origins, customs, and styles of living, and provides a sense of identity and common language. Members' shared history and experiences shape the group's values, goals, expectations, beliefs, perceptions, and behaviors.[441]

When cultural competency is not addressed, health care may be compromised. There are many examples of cultural insensitivity/ignorance on the part of health care providers:

> In an effort to be friendly, a doctor greets an African American grandmother by her first name. The woman does not respond warmly to what she considers to be disrespectful behavior.
>
> A Thai patient speaks to an intake worker who takes notes in red ink. The patient is alarmed because in Thailand red ink is only used in criminal proceedings.
>
> A Laotian patient at a rural California clinic is told to give her child one teaspoon of medicine every four hours. The only spoon in her house is a porcelain soup spoon; the medication runs out long before the prescribed ten days.[442]

The result is the creation of additional obstacles to health care, which in turn results in inefficient and inappropriate use of health care resources. Patients come to rely on the emergency room because they avoid seeing a doctor until medically necessary; they use traditional remedies in addition to or in lieu of Western medicine because of a reluctance to trust the doctor; and they do not comply with prescribed treatments because of a lack of understanding or trust.[443]

As one element of cultural incongruence, linguistic barriers play an important role in the inability to access quality medical care, particularly for Hispanics and Asian Americans. Potential mechanisms to address linguistic and cultural barriers in health care services are provided in the protections of title VI of the Civil Rights Act of 1964.[444] However, a survey of State medicaid managed care by the Association of Asian Pacific Community Health Organizations (AAPCHO) found variability in enforcement of the requirements for linguistically appropriate care. The survey also found an absence of uniform guidelines, limited availability of accurate information on the number of enrollees who do not speak English, and a lack of data on the actual costs incurred in providing bilingual services.[445]

The lack of interpretive services ultimately results in inequities in treatment and service utilization rates. Findings from a study of Chinese women in California indicate that women who do not speak English fluently are less likely to have had mammograms.[446] Additionally, the Korean Health Survey found that only 29 percent of Korean American women had had breast exams within the previous year, compared with 50 percent of all American women; only 35 percent had ever had Pap smears, compared with half of all women in the United States.[447]

Health care services are often unacceptable for minority groups because they have been designed by members of the medical community who are not of the same culture. In particular, women from racial and ethnic minority groups often face difficulties overcoming the cultural barriers that may preclude them from accessing health services. For example, the experiences, cultural norms, and roles of Hispanic women are too frequently ignored, fostering a sense of frustration and increasing distrust of the health care

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[440] HHS, "HHS and Cultural Competency," draft report, p. 1. Hispanic Agenda for Action Steering Committee identified cultural competency as an issue that must be addressed by all components of HHS. *See* chap. 4, for a discussion of HHS initiatives.

[441] Sally Kohn, "Dismantling Sociocultural Barriers to Care," *Healthcare Forum Journal*, May/June 1995, p. 30.

[442] Ibid., p. 32.

[443] Ibid.

[444] Grace M. Wang, "Managed Care and Asian Pacific Island Women," *Journal of the American Medical Women's Association*, vol. 51 no. 4 (August/October 1996), p. 146.

[445] Ibid.

[446] Ibid., citing to A. Chen, R. Lew, V. Thai, et al., "Behavioral Risk Factor Survey of Chinese-California, 1989."

[447] Ibid., citing to E. Han, "Korean Health Survey in Southern California: A Preliminary Report on Health Status and Health Care Needs of Korean Immigrants," a paper presented at the Asian American Health Forum Conference in Bethesda, MD, Nov. 17, 1990.

system.[448] Traditional health care beliefs and practices of Hispanic women are rarely recognized or integrated, nor are Hispanic women included in the process of developing the services:

> Although Hispanic women's roles, daily lived experiences and forms of social support have been considered relevant in understanding their health care needs, the literature has most often focused on issues that relate to their reproductive roles. While the current literature provides valuable knowledge, most studies lack a theoretical perspective that (1) permits an analysis of the sociopolitical and cultural environment of Hispanic women, (2) recognizes that health care organizations, structures, and ideologies are often oppressive to women, and (3) values political action and social change as a precursor to women's health.[449]

Asian Americans, particularly those who are recent immigrants, often face similar difficulties when seeking health care.[450] For many Asian Americans and Pacific Islanders, Western biomedical health care practices conflict sharply with traditional health and healing practices.[451] As demonstrated earlier, among many Southeast Asian refugees, traditional concepts of illness, folk remedies, and unfamiliarity with the U.S. health system combine with linguistic barriers to create a pattern of "unexpressed health needs."[452] For example, the concept of waiting 2 or 3 weeks for an appointment may seem inappropriate to many Southeast Asians, so it may be difficult getting them to accept the appointment system.[453] It has also been argued that cultural barriers are built into the way Western medicine is practiced, with a biomedical model emphasizing isolation and the treatment of specific ailments rather than a more holistic approach.[454] Often the cultural beliefs of Asian Americans are cited as the reason for their underuse of services; however, this perspective nullifies the responsibility of the health system to adapt to the increasing multiculturalism of society.[455]

The idea of cultural competency merits further examination in the context of immigrant health. Immigrants face barriers to health care access not only from the standpoint of language difficulties, but also from less tangible social and legal isolation. Cultural values and role issues, along with unique fears and stressors, must be taken into account when assessing the health care needs of the immigrant community. There need to be studies done from a qualitative perspective that can bring understanding to immigrants' daily experiences with regard to their immigration and refugee status, roles, forms of social support, and how these experiences influence their health, health care access, and health care use.[456] Additionally, efforts must be made to overcome barriers created by increasing diversity.

Sociocultural contexts of individuals' lives must be taken into consideration when designing health programs if they are to adequately meet the needs of the communities they serve. Culturally competent care is compromised because of prejudice, racism, lack of understanding, and cultural myths.[457] The result is that many racial and ethnic minorities attempt to seek care outside the norm of public health care, such as in more expensive private facilities, if they can afford it; through folk medicine or nontraditional healing processes; or if these are not available options, only when an acute need is present.[458]

Further, for cultural competence to be completely integrated into health service delivery, not only must health care providers understand the cultural context of their patients, but they must recognize how their own behaviors and practices are influenced by culture. According to one minority health expert:

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448 Juarbe, "Access to Health Care for Hispanic Women," p. 26.

449 Ibid., p. 24.

450 Many Asian Americans, particularly third, fourth and fifth generation Americans, are very assimilated and accept Western medical practices. Cultural insensitivity also includes instances where assumptions are made about an individual's English proficiency or degree of assimilation based solely on his or her race or ethnicity.

451 Mayeno and Hirota, "Access to Health Care," 354.

452 Ibid.

453 Ibid., p. 354–55.

454 Ibid., p. 355.

455 Ibid.

456 Juarbe, "Access to Health Care for Hispanic Women," p. 27.

457 Ibid., p. 26.

458 Ibid.

To fully appreciate cultural differences, providers must also recognize and acknowledge how their day-to-day behaviors and thoughts have been shaped by cultural norms and values of the dominant society, and reinforced by families, peers and social institutions. A more purposeful self-examination of cultural influences can lead to a better understanding of the impact of culture on one's own life. Only then can the complexities of cross-cultural interactions be fully appreciated.[459]

In addition, the development of cultural competence must occur beyond the level of the individual provider, to include local, State, and Federal health care agencies. All health care programs must assess their level of cultural competence and devise strategies for achieving broad based cultural inclusion if equality in health care is to be attainable.

Profile of the Health Care Industry

"Authorities who predicted that all Americans would have access to a single health care system were wrong. The separate and unequal health care system is alive and well, thriving in an environment that views health care as a marketplace commodity to be bought rather than as a societal good to be provided as a matter of right."[460]

The health care industry has several components, including health care professionals, facilities, financing organizations, and research organizations. Federal, State, and local agencies are involved in the delivery and oversight of health care services in the United States. The structure of the industry, and changes within it, may affect the health status of certain groups differently.

Health Care Professionals

Race and Ethnicity

According to the Principal Deputy Assistant Secretary for Health and the U.S. Department of Health and Human Services, "Recruitment, retention, training, and promotion of racial and ethnic minorities within the Nation's health professions workforce will not only help eliminate disparities in health care received by all minorities, it will improve the health of *all* Americans."[461] However, despite initiatives to increase minority enrollment in health professional schools, and to improve the health and science education of students at earlier ages, there remains a shortage of minority health care professionals.

There were 737,764 medical doctors in the United States in 1996.[462] However, there are disparities in where doctors are located. According to HHS, minorities are likely to live in medically underserved areas. For example, poor urban communities with high proportions of blacks and Hispanics average only 24 physicians per 100,000 people; however, poor urban communities with low proportions of blacks and Hispanics average 69 physicians per 100,000 people.[463] To address the shortage of health care providers in these areas, HHS has established the National Health Service Corps Program through which culturally competent primary care professionals are recruited to practice in underserved communities.[464] The benefits of such programs are numerous. As one proponent states, "There is no doubt that trainees who spend a significant amount of time in an underserved community are more likely to understand those communities better, relate to those communities better, and be more likely to return to serve in those communities in the long term."[465]

Programs such as the National Health Service Corps should place an emphasis on underserved minority communities, and on the recruitment of minority health care providers. HHS data show that minority physicians are more likely than other doctors to serve minority patients. Black physicians are five times more likely than other doctors to treat black patients. Similarly, Hispanic physicians are 2.5 times more likely than other doctors to treat Hispanic

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[459] Stinson letter, p. 4.

[460] Geraldine Dallek, "Health Care for America's Poor: Separate and Unequal," *Clearinghouse Review*, special issue, summer 1986, p. 362.

[461] Nicole Lurie, "Putting the Right People in the Right Places: Minority Health Professionals Service Community Needs," *Closing the Gap*, May/June 1999, p. 1.

[462] NCHS, *Health, U.S., 1998*, p. 324.

[463] HRSA, *Health Care Rx*, pp. 10–11.

[464] *See* chap. 4.

[465] Carol Greene, U.S. Senate Committee on Health, Education, Labor and Pensions, statement at the Capitol Hill Health Policy Roundtable, "Health Professions Education in Underserved Communities: Supporting Partnerships Through Public Policy," Washington, DC, June 3, 1999.

patients.[466] In addition, black, Asian American/Pacific Islander, and Hispanic physicians are "far more likely to treat Medicaid or uninsured patients than white physicians from the same area."[467]

A lack of minority doctors may lead to limited access to health care for minority patients.[468] One study of California communities showed that, independent of income, communities that had a high proportion of black and/or Hispanic residents were likely to have a shortage of physicians. Because black and Hispanic doctors generally tend to practice in poor areas and areas with a high proportion of residents of their own race or ethnic group, minority doctors fill an important role in the community.[469] The authors of the study conclude that a decrease in the number of physicians from minority groups may result in reduced access to health care, reduced health, and reduced well-being for a large portion of the minority population.[470] Another author noted that blacks (and other minorities) have limited sources of health care available to them:

> Black communities are much more likely to have a limited number of health care providers. This includes both inner cities and rural areas in relatively poor states. As of 1985, for example, one-third of the 750 American counties with the highest proportion of black population had been designated by the federal government as "critical shortage areas" for primary care physicians; this is half again as common as for all other counties in the country. Consequently a disproportionate number of blacks rely on hospitals and community health centers to provide primary care.[471]

This author notes that even when health care services are available, "blacks may face racial discrimination that makes it difficult for them to obtain care or limits their choices among health care providers."[472]

Thus, it is of grave importance to increase the number of minority doctors and health professionals. According to a recent survey of medical school graduates, racial/ethnic minority physicians are more likely to provide health care to poor and uninsured patients and to practice in underserved areas.[473] An article in the *Journal of the American Medical Association* confirmed that minority physicians:

- Have a high proportion of minority patients.
- Have a "greater willingness" to practice in lower income areas.
- Enter primary care specialties (such as general internal medicine, family practice, and general pediatrics) at higher rates than non-minority physicians (thus providing continuity of care and having "the greatest potential to improve the health status of populations"[474]).
- Are more culturally sensitive than other physicians.[475]

Thus, minority physicians "have had a positive impact on increasing the access to care of minority populations."[476] Because minority physicians often share and understand the cultural background of their patients, they understand the ethnic differences in attitudes, beliefs, and behaviors that can affect health status and how patients communicate their health problems.[477] Further, students who overcome financial barriers to medical training, who are often minorities, are more likely to work in medically underserved areas and are more likely to understand how

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[466] HHS, *Health Care Rx*, p. 12.

[467] Ibid., p. 13.

[468] Miriam Komaromy et al., "The Role of Black and Hispanic Physicians in Providing Health Care for Underserved Populations," *New England Journal of Medicine*, vol. 334 (May 16, 1996), pp. 1305–10.

[469] Ibid.

[470] Ibid.

[471] Mark Schlesinger, "Paying the Price: Medical Care, Minorities, and the Newly Competitive Health Care System," *Milbank Quarterly*, vol. 65, suppl. 2 (1987), p. 276.

[472] Ibid., p. 277.

[473] Lurie, "Putting the Right People in the Right Places," p. 1.

[474] Herbert W. Nickens, "The Rationale for Minority-Targeted Programs in Medicine in the 1990s," *Journal of the American Medical Association*, vol. 267, no. 17 (May 6, 1992), pp. 2390, 2395.

[475] Ibid., p. 2395. *See also* Donald L. Libby, Zijun Zhou, and David A. Kindig, "Will Minority Physician Supply Meet U.S. Needs? Projection for Reaching Racial Parity of Physicians to Population," *Health Affairs*, July-August 1997 (hereafter cited as Libby et al., "Will Minority Physician Supply Meet U.S. Needs?").

[476] Nickens, "Minority-Targeted Programs," p. 2395.

[477] Peréz-Stable et al., "The Effects of Ethnicity and Language," p. 1212.

cultural and economic circumstances affect health.[478]

An examination of the demographic composition of the work force in the health care industry reveals that minorities are underrepresented in the health professions that require extensive training. As shown in table 2.6, African Americans are most likely to be nursing aides, orderlies, and attendants, holding 34 percent of these jobs. Hispanics are most likely to be in the field of dental laboratory and medical appliance technician, and account for 12.6 percent of that occupational category.[479] While African Americans are well represented in some of the health professions requiring substantial formal education, such as dietitian and social worker, they remain underrepresented as many other professionals, including speech therapists, dentists, pharmacists, and physicians. Similarly, Hispanics are well represented among dental assistants and dental laboratory and medical appliance technicians, but are not found in large numbers in other health professions requiring formal training.[480]

Recently much emphasis has been placed on the racial composition of medical schools and other institutions for training in health-related fields.[481] As shown in figure 2.4, white students far outnumber minority students in all health-related fields. Of the almost 67,000 students studying allopathic medicine in 1995–96, 67 percent were white. Asian Americans accounted for 11 percent of such students, while blacks, Hispanics, and Native Americans represented 8 percent, 7 percent, and 1 percent, respectively, of the student population.[482] Similarly, white students accounted for 68 percent of the dentistry students, while Asian Americans, blacks, and Hispanics accounted for 21 percent, 6 percent, and 5 percent of the dental students in 1995–96.[483] It should be noted that while Asian Americans as a group are no longer considered "underrepresented" in many fields of medicine, certain Asian subpopulations, such as Native Hawaiians, Pacific Islanders, and Southeast Asians, are still significantly absent.[484]

Table 2.6
Minority Employment in Health Professions, 1998

Health profession	% Black	% Hispanic
Speech therapist	1.9	6.3
Dentist	2.8	2.0
Dental hygienist	3.9	3.9
Pharmacist	4.1	5.1
Physical therapist	4.2	5.4
Physician	4.9	4.8
Dental assistant	6.1	12.1
Occupational therapist	6.5	0.7
Dental laboratory and medical appliance technician	6.8	12.6
Radiologic technician	8.2	2.0
Registered nurse	9.3	3.2
Psychologist	10.2	4.0
Physician assistant	10.6	2.8
Respiratory therapist	11.7	2.0
Clinical laboratory technologist/ technician	15.0	6.4
Licensed practical nurse	17.4	5.8
Dietitian	18.2	4.3
Social worker	23.4	6.4
Health aide (except nursing)	24.4	9.3
Nursing aide, orderly, attendant	34.0	9.8

SOURCE: Miguel R. Kamat, "Educating Health Professionals: Are We Failing Minorities?" *Closing the Gap*, May/June 1999, p. 8 (using Current Population Survey data).

One factor that contributes to the dearth of minorities in medical professions is the high cost of medical education. Because minorities are more likely to come from low-income families, they are less likely to be able to afford medical education. This presents not only a financial barrier, but a psychological one. According to one commentator:

> For a youngster from a poor family that is earning $20,000 or less, the idea of going to medical school and owing more than $100,000 in debt at the time of graduation is a critical psychological impediment, much more so for such a student than for a student from a middle income family. So again, the major im-

[478] Claude Earl Fox, "HRSA Opens Doors for Minorities in Health Professions," *Closing the Gap*, May/June 1999, p. 3 .

[479] Miguel R. Kamat, "Educating Health Professionals: Are We Failing Minorities?" *Closing the Gap*, May/June 1999, p. 8.

[480] Ibid.

[481] American Association of Medical Colleges, *Project 3000 by 2000: Progress to Date, Year Four Progress Report*, April 1996 (hereafter cited as AAMC, *Project 3000 by 2000*).

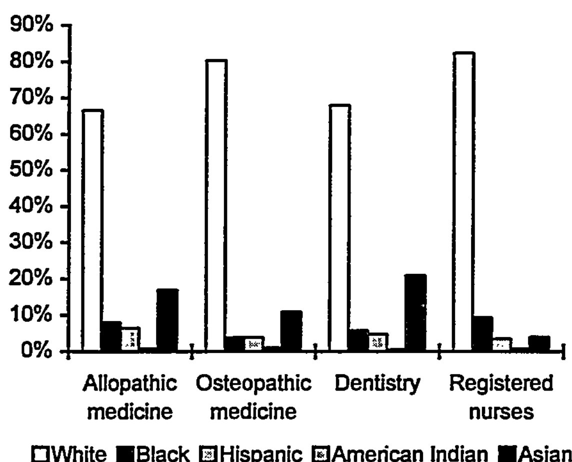
[482] NCHS, *Health, U.S., 1998*, p. 331.

[483] Ibid.

[484] Stinson letter, p. 5.

pediment for minorities and the poor is the cost of medical education and the lack of available financial resources for scholarships.[485]

Figure 2.4
Enrollment of Minorities in Schools for Selected Health Occupations, 1995–1996



SOURCE: U.S. Department of Health and Human Services, National Center for Health Statistics, *Health, United States, 1998 with Socioeconomic Status and Health Chartbook*, 1998, pp. 331–32.

Another barrier to entering medical school and other postgraduate health professional programs is lack of preparation and academic skills. According to research by the Association of American Medical Colleges (AAMC), the Nation's schools and colleges have not academically prepared minority students for health professional schools.[486] Although the proportion of minorities taking advanced math and science courses doubled between 1982 and 1992, compared with Asian Americans and whites, African Americans, Hispanics, and Native Americans still are more likely to be in remedial math classes in high school.[487] There also are substantial differences between whites' and minorities' scores on achievement tests. Using data from the U.S. Department of Education's National Assessment of Education Progress, the AAMC estimated that there are approximately 334,000 white 17-year-olds with advanced skills in the science, and only 3,500 black and 4,500 Hispanic 17-year-olds with equivalent skills.[488] According to the Administrator of the Health Resources and Services Administration:

> Before minorities can become health professionals, they have to become health profession students. This is a feat often more difficult for racial and ethnic minorities and students from disadvantaged backgrounds. Math and science requirements are demanding. Test scores must be high. Students have to be motivated. They also have to believe they can succeed.[489]

The American Medical Association has recommended several measures to increase minority representation in medicine, including:

> (1) expansion of recruitment efforts, including special premedical and precollegiate programs for minority students, (2) greater government financial aid to those in need at both the collegiate and medical school levels, (3) affirmative action in medical school admission and faculty-hiring decisions, (4) more supportive academic programs for minority students (through tutorials and academic assistance, decelerated schedules as required, and early orientations), and (5) competent and sensitive student counseling and advisory services.[490]

According to HHS, several schools and training programs that have received funds from HHS have made progress in increasing the number of minorities graduating from their programs. Minorities represent 33 percent of the professionals in general practice dentistry residency training programs and 32 percent of those

[485] Louis Sullivan, president, Morehouse School of Medicine, telephone interview, May 2, 1999, p. 11.

[486] Herbert Nickens and Timothy Ready, "Project 3000 by 2000: Expanding Our Network," *Closing the Gap*, May/June 1999, p. 4 (hereafter cited as Nickens and Ready, "Expanding Our Network").

[487] Kamat, "Educating Health Professionals," p. 9.

[488] Nickens and Ready, "Expanding Our Network," p. 4

[489] Fox, "HRSA Opens Door," p. 2. HRSA has implemented several programs aimed at recruiting minorities in medical professions. For example, the Health Careers Opportunity Program was designed to increase the number of minority physicians, dentists, nurses, and other health professionals. *See* chap. 4.

[490] AMA, "Black-White Disparities in Health Care," p. 2346.

in physician assistant training programs.[491] In addition, minorities account for 26 percent, 21 percent, 20 percent, and 19 percent, respectively, of the persons enrolled in HHS-funded public health traineeships, advanced nurse education, nurse special projects, and preventive medicine residency.[492]

To address the shortage of minority students in medical schools, the American Association of Medical Colleges instituted Project 3000 by 2000 in 1991. The goal of the project is to "increase the number of underrepresented minority (URM) students entering the nation's 125 medical schools each year to 3,000 by the year 2000."[493] The AAMC has found that underrepresentation of minorities in health professions is related to two factors: (1) a scarcity of minorities who are interested in the health professions, and (2) the relatively small number of minority students who have the academic qualifications needed to pursue medical study. According to the AAMC, these factors are due to "educational disadvantages that disproportionately affect the same minority communities that have borne the brunt of prejudicial treatment throughout most of American history."[494]

Progress reports for Project 3000 by 2000, as it nears the end of its projected goal date, indicate that although its ultimate goal has not been reached, progress has been made in minority student enrollment. The AAMC attributes the lack of goal attainment to some extent to the affirmative action backlash of the early 1990s. Despite this, there has been an 18 percent increase in the number of underrepresented minority matriculants since the project began, and the number of underrepresented minority applicants has increased by 24 percent.[495] Project 3000 by 2000 is just one example of the types of initiatives necessary to foster an increase in minority participation in medical professions. This initiative, and other similar ones supported by the National Science Foundation and the National Institutes of Health, indicate a recognition of the necessity of an ethnically and racially diverse medical community.[496]

Nonetheless, according to a recent article in HHS' Office of Minority Health's newsletter, *Closing the Gap*, the United States is "nowhere near eliminating the gaping racial disparities in health and education that have plagued our nation" and there is now "a backlash against initiatives designed to enhance racial and ethnic diversity in higher education and the professions."[497] According to the article, efforts to increase minority enrollment in medical schools have been in place since the 1970s. However, elementary schools, high schools, and colleges failed "to produce a sufficient number of academically well-prepared minority students."[498] Thus, the AAMC's approach to increasing minority enrollment in health professional schools includes addressing the academic of needs of students from the precollege years through postgraduate medical education, and creating partnerships among elementary, junior high, and high schools; colleges; health professional schools; and other organizations.[499]

The American Dental Association (ADA) similarly is aware of the need to address diversity in its programs and initiatives, and has developed a program to increase minority dental school enrollments, which is modeled after the AAMC's Project 3000 by 2000.[500] According to its strategic plan for 1998 to 2001, "the ADA is committed to creating an inclusive environment that values and embraces diversity."[501] For example, in 1997 the ADA published a *Resource Kit for Recruitment of Women Dentists into Or-*

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[491] HHS, *Health Care Rx*, p. 16.

[492] Ibid.

[493] AAMC, *Project 3000 by 2000*, p. 1.

[494] Ibid.

[495] Information on "Project 3000 by 2000" was obtained through correspondence with Timothy Ready of the Association of American Medical Colleges. Statistics were taken from William T. Butler, MD, "Project 3000 by 2000: Progress during Tumultuous Times," *Academic Medicine*, vol. 74, no. 4 (April 1999), pp. 308–09. *See* USCCR, *The Health Care Challenge*, vol. II, chap. 3, for a discussion of medical school admissions.

[496] *See* Butler, "Project 3000 by 2000." *See also* USCCR, *The Health Care Challenge*, vol. II, chap. 3.

[497] Nickens and Ready, "Expanding Our Network," p. 5.

[498] Ibid., p. 4.

[499] Ibid., p. 5.

[500] John S. Zapp, executive director, American Dental Association, letter to Mireille Zieseniss, USCCR, Apr. 5, 1999, pp. 1–2 (hereafter cited as Zapp letter).

[501] American Dental Association, *Strategic Plan: 1998–2001*, "Guiding Principles, Values and Beliefs." The ADA also believes that "[e]nhancing the quality, availability, affordability and utilization of oral health care benefits the public's general health and well-being." Ibid.

ganized Dentistry, and, in 1998, the ADA conducted a session on cultural diversity in its annual conference on membership risk.[502] In addition, the ADA has done several surveys addressing race, ethnicity, and gender issues in dentistry.[503]

The 1996 ADA survey of all individuals enrolled in or who graduated from an accredited dental school in the United States revealed several reasons why an increase in the number of minority dentists is beneficial. Minority dentists are more likely to serve patients of their own race or ethnicity. In fact, in the study, 62 percent of the patients of black dentists were black;[504] 45 percent of the patients of Hispanic dentists were Hispanic;[505] 25 percent of the patients of Asian American dentists were Asian, a larger percentage of Asian patients than were served by dentists of any other race or ethnicity;[506] and 10 percent of the patients of American Indian dentists were American Indian. Only 1 percent of the total patients that dentists of other races and ethnic backgrounds served were American Indian.[507]

Minority dentists in private practice are also more likely than whites to provide free or reduced rate dental care to patients who may have difficulty in paying for, or otherwise obtaining, dental care. For example, 27 percent of black private practitioners, 25 percent of American Indian private practitioners, 21 percent of Hispanic private practitioners, and 19 percent of Asian American private practitioners provided free or reduced rate dental care to HIV/AIDS patients, but only 15 percent of white private practitioners did.[508] Similarly, private practitioners of minority groups are more likely to provide free or reduced rate dental care to migrant workers (31 percent, 24 percent, 24 percent, and 20 percent of Hispanic, Asian, American Indian, and black dentists served migrant workers, respectively) than were whites (of whom only 19 percent served migrant workers).[509]

At the same time, minorities who went to dental school have lower incomes, less prestigious jobs and, in the case of blacks, are less likely to actually be practicing dentistry than whites. Fifty six percent of black, 52 percent of Hispanic and Asian American, and 42 percent of American Indian dentists make less than $100,000 gross annual income, compared with 38 percent of whites.[510] Minority dentists are also less likely to be specialists than whites. Fourteen to 16 percent of black, Hispanic, Asian American, and American Indian dentists are specialists; but 18 percent of whites are.[511] Finally, 3 percent of blacks who graduated from dental school were not practicing, compared with 1 or 2 percent of whites or other persons of color.[512]

Gender

Like racial and ethnic minorities, women also traditionally have been absent from the high ranks of the health care profession, particularly as physicians and researchers. In 1995 women made up only 20.7 percent of all physicians. While this number is up from 11.6 percent in 1980, it demonstrates a continuing scarcity of females in medicine. Of these women, 84.7 percent are in patient care, and only 1.6 percent are in research positions; in fact, in 1995, women

[502] Zapp letter, enclosure, "Summary of Diversity Initiatives: American Dental Association," p. 3.

[503] *See, e.g.*, American Dental Association (ADA), "1995 Survey of Dentists: A Comparison of Male and Female Dentists: Work-Related Issues," November 1997; ADA, "1996 Dentist Profile Survey: Black Respondents," February 1998 (hereafter cited as ADA, "Blacks"); ADA, "1996 Dentist Profile Survey: Hispanic Respondents," February 1998 (hereafter cited as ADA, "Hispanics"; ADA, "1996 Dentist Profile Survey: White Respondents," February 1998 (hereafter cited as ADA, "Whites"); ADA, "1996 Dentist Profile Survey: American Indian Respondents," March 1998 (hereafter cited as ADA, "American Indians"); ADA, "1996 Dentist Profile Survey: Asian Respondents," March 1998 (hereafter cited as ADA, "Asians").

[504] ADA, "Blacks," figure 11, p. 12.

[505] ADA, "Hispanics," figure 11, p. 12.

[506] ADA, "Asians," figure 11, p. 12.

[507] ADA, "American Indians," figure 8, p. 11.

[508] ADA, "Blacks," table 9, p. 20; ADA, "American Indians," table 9, p. 17; ADA, "Hispanics," table 9, p. 20; ADA, "Asians," table 9, p. 20; ADA, "Whites," table 8, p. 20.

[509] ADA, "Hispanics," table 9, p. 20; ADA, "Asians," table 9, p. 20; ADA, "American Indians," table 9, p. 17; ADA, "Blacks," table 9, p. 20; ADA, "Whites," table 8, p. 20.

[510] ADA, "Blacks," figure 6, p. 8; ADA, "Hispanics," figure 6, p. 8; ADA, "Asians," figure 6, p. 8; ADA, "American Indians," figure 5, p. 8; ADA, "Whites," figure 6, p. 8.

[511] ADA, "Blacks," table 6, p. 6; ADA, "Hispanics," table 6, p. 6; ADA, "Asians," table 6, p. 6; ADA, "American Indians," table 6, p. 6; ADA, "Whites," table 5, p. 6.

[512] ADA, "Blacks," table 6, p. 6; ADA, "Whites," table 5, p. 6; ADA, "Hispanics," table 6, p. 6; ADA, "Asians," table 6, p. 6; ADA, "American Indians," table 6, p. 6. For a statistical summary, *see* app. 4.

Table 2.7
Female Physicians by Activity, 1980 and 1995

	1980		1995	
	Total	Women	Total	Women
Total physicians	*467,679*	*54,284*	*720,325*	*149,404*
Activity:				
Patient care	376,512	39,969	582,131	126,583
Office-based practice	272,000	20,609	427,275	79,843
Hospital-based practice	104,512	19,360	154,856	46,740
Resident/fellows	62,042	13,332	96,352	32,797
Full-time staff	42,470	6,038	58,504	13,943
Other professional activity	38,404	4,737	43,312	7,621
Medical teaching	7,942	1,090	9,469	2,142
Administration	12,209	1,178	16,345	2,399
Research	15,377	2,077	14,340	2,442
Other	2,876	392	3,158	638
Not classified	20,629	4,030	20,579	5,924
Inactive	25,744	3,773	72,326	8,755
Unknown	6,390	1,775	1,977	521

SOURCE: American Medical Association, "Physician Characteristics and Distribution in the U.S., 1996–97," table ee.

only made up 17 percent of all medical researchers (see table 2.7).[513]

These numbers are expected to increase, as more women are entering medical professions than ever before. In academic year 1997–98, women made up 42.6 percent of all students enrolled in medical school and 41.5 percent of all graduates.[514] Despite gains in medical school enrollment, women currently make up only 11 percent of clinical faculty in medical schools and only 9 percent of tenured professors.[515] Women's salaries in academic medical institutions are 5 to 11 percent lower than their male counterparts, and among practicing physicians, women's salaries are 30 percent lower for comparable jobs.[516] This is true in dentistry as well. Women dentists earn, on average, $26,000 (22 percent) less per year than men, even when controlling for age and experience.[517]

Furthermore, there still appears to be a clustering of women in specific areas of medicine. Several scholars have theorized that this is due to the categorization of medical students and the subsequent steering of female students toward the more "accepted" specialties such as pediatrics and general practice.[518] One study concluded that medical schools do indeed steer women into traditional medical fields. Only 8 percent of the women in the study had originally named pediatrics as their chosen specialty, but one-third of the respondents eventually entered pediatric residencies.[519] As one commentator states, "If this trend continues, medicine will become a two-tiered system, with women in the moderately remunerated areas of family medicine and primary care, and men in the richly rewarding

[513] American Medical Association, Department of Data Survey and Planning. *Physician Characteristics and Distribution in the US, 1996–97* (Chicago, IL: American Medical Association, 1997), p.14 (hereafter cited as AMA, *Physician Characteristics 1996–97*).

[514] Barbara Barzansky, Harry S. Jonas, and Sylvia I. Etzel, "Educational Programs in US Medical Schools, 1997–1998," *Journal of the American Medical Association*, vol. 280, no. 9 (Sept. 2, 1998), p. 806 (hereafter cited as Barzansky et al., "Educational Programs in US Medical Schools.")

[515] Elena V. Rios, and Clay E. Simpson, Jr., "Curriculum Enhancement in Medical Education: Teaching Cultural Competence and Women's Health For a Changing Society," *Journal of the American Medical Women's Association*, vol. 53, no. 3 (suppl. 1998).

[516] Ibid.

[517] L. Jackson Brown and Vicki Lazar, "Differences in Net Incomes of Male and Female Owner General Practitioners," *Journal of the American Dental Association*, vol. 139 (March 1998), pp. 373–78.

[518] Leslie Laurence and Beth Weinhouse, *Outrageous Practices: The Alarming Truth About How Medicine Mistreats Women* (New York: Ballantine Books, 1994), p. 37.

[519] *See* ibid.

surgical subspecialties."[520] Almost 60 percent of the women practicing medicine in 1995 were clustered in five areas: internal medicine, pediatrics, family practice, obstetrics/gynecology, and psychiatry.[521]

It is often assumed in the male-dominated medical arena that women are "good with patients," so female physicians are frequently guided toward clinical medicine, while their male counterparts dominate the more lucrative and prestigious research arena.[522] The difficulty women face breaking into medical research is compounded by the uneven distribution of grant support. Women receive only 21.5 percent of all research project funds, and their grant awards are, on average, $30,000 less than those of male researchers.[523] In addition to the lack of research funding, women face other barriers in biomedical careers. The Office of Research on Women's Health (ORWH) at the National Institutes of Health (NIH) has made the development of research opportunities and support for recruitment and advancement of women in biomedical careers one of its main objectives.[524] The ORWH has identified nine general barriers and issues that are common to female biomedical professionals, regardless of race, ethnicity, culture, or scientific discipline. Among the barriers to biomedical success are low visibility and the lack of role models and mentors; reentry into a biomedical career after professional separation; family responsibilities; and sexual discrimination and sexual harassment.[525]

Despite the growing numbers of women practicing medicine, Hispanic women are still severely underrepresented, making up less than 2 percent of those in health professions that require advanced degrees.[526] Current rates of medical school enrollment among Hispanic women suggest that this percentage is not likely to change unless these women are actively recruited into medicine.[527] In academic year 1997–98, Hispanic women made up less than 3 percent of all medical students.[528]

In much the same way that minority physicians have had a positive impact on minority communities, women physicians have the potential to affect positively female patients. Increasing the numbers of women in medicine has the potential to encourage the development of multidisciplinary and community-based curricula, contribute to the expansion of information on women's health, and increase attention to women's health research.[529] Evidence also indicates that the practices of women physicians also have the potential to improve the quality of patient care, particularly for female patients. Patient-doctor communication has been cited as an important mechanism for effective health care treatment. For example: "Recent evidence of disparities in the use of major diagnostic and therapeutic interventions for women compared with men, particularly in terms of coronary heart disease, may be a reflection of failed communication between patients and their physicians that might be partly attributable to gender."[530]

There are many potential benefits to having female health care providers, including increased access to diagnostic procedures for women's specific health needs. A study of medical visits also revealed that female physicians spend more time with their patients, particularly with women patients:

> Female physicians engaged in significantly more positive talk, partnership building, question asking, and

[520] *See* ibid. *Also see* USCCR, *The Health Care Challenge*, vol. II, chap. 3, for a discussion of the need for OCR policy guidance on affirmative action measures for minorities and women in medical schools admission and placement.

[521] AMA, *Physician Characteristics 1996–97*, p.14.

[522] Laurence and Weinhouse, *Outrageous Practices.*

[523] Ibid., citing to "Women in NIH Extramural Grant Programs," Fiscal Years 1981 to 1992, Division of Research Grants, National Institutes of Health.

[524] HHS, National Institutes of Health, Office of Research on Women's Health, "Biomedical Career Development for Women," fact sheet, revised November 1998.

[525] Ibid. For a more indepth discussion of NIH initiatives to address women in biomedical careers, *see* chap. 4.

[526] Ruth E. Zambrana, "The Underrepresentation of Hispanic Women in the Health Professions," *Journal of the American Women's Medical Association*, August/October 1996, pp. 147–52.

[527] Ibid.

[528] Barzansky et al., "Educational Programs in US Medical Schools," p. 807.

[529] Rios and Simpson, "Curriculum Enhancement in Medical Education."

[530] Sheryle J. Gallant, Gwendolyn Puryear Keita, and Renee Royak-Schaler, eds., *Health Care for Women: Psychological, Social, and Behavioral Influences* (Washington, DC: American Psychological Association, 1997), p. 57.

information giving, both biomedical and psychosocial. Patients, both male and female, engaged in significantly more positive talk and more partnership talk and were more likely to ask questions, give substantially more biomedical information, and engage in almost twice as much psychosocial talk when with female rather than male physicians. . . . This effect was especially evident when female doctors were with female patients.[531]

This extended interaction could not only have a positive effect on the willingness of women to receive medical attention, but also on the quality of care women receive.

Health Care Facilities

In 1996 there were 6,201 hospitals in the United States providing more than 1 million hospital beds. Of these hospitals, 290 were operated by the Federal Government and the remaining 5,911 were non-Federal hospitals.[532] In 1994 there were more than 3,000 mental hospitals/organizations, including State and county mental hospitals, private psychiatric hospitals, non-Federal hospital psychiatric services, Department of Veterans Affairs psychiatric services, and residential treatment centers.[533] In addition, in 1996 there were more than 17,000 nursing homes in the United States.[534] Despite the many choices of facilities, it has been argued that discrimination continues to exist in health care delivery, as the lingering effect of a history of discriminatory practices.[535] According to one scholar:

Federal efforts at eliminating segregation [in nursing homes] have been more limited [than in hospitals], given the limited involvement of the Medicare program and the direct financing of long term care. In addition there is far more public ambivalence in forcing the issue of integration for nursing homes. There is a persistent assumption that cultural differences explain the differences in use of nursing homes between whites and nonwhites, even though this does not hold up well under scrutiny.[536]

This erroneous assumption makes it imperative that OCR become involved in resolving instances of discrimination in nursing homes and other health facilities to ensure that practices resulting in differential treatment are eliminated.

Hospitals

Prior to the 1960s, hospitals were voluntary organizations and, as such, did not face the same legal requirements as public institutions. In addition, hospital medical staffs were self-governing, which gave them freedom to select members, choose patients, and adopt payment policies as they saw fit.[537] Health care services and providers also were segregated in most of the country. Separate medical schools, nursing programs, and hospitals for blacks were developed to provide services to those who were discriminated against.[538]

Another important facility providing health care services as well medical research is the teaching hospital, a facility that plays a major role in serving underserved populations. According to the Association of American Medical Colleges, 52 percent of patients hospitalized in major teaching hospitals have one or more risk factors for underservice.[539] Risk factors include being medically indigent, of a racial or ethnic minority group, or poor. The AAMC also concludes that as the number of uninsured or underinsured people in the United States continues to grow, and hospital survival increasingly becomes a business venture, teaching hospitals will be less able to provide care to these populations.

Currently, teaching hospitals receive funds from various sources: direct and indirect medical education, known as graduate medical education payments which provide for the salaries and training of residents and faculty, and for overhead expenses; and disproportionate share adjustments which are given to hospitals that serve a high volume of medicare and medicaid

[531] Ibid., p. 61.

[532] NCHS, *Health, U.S., 1998,* p. 334.

[533] Ibid., p. 335.

[534] Ibid., p. 339.

[535] Smith, "Racial Inequities."

[536] David Barton Smith, "The Racial Integration of Health Facilities," *Journal of Health Politics, Policy and Law,* vol. 18, no. 4 (winter 1993), pp. 851–69.

[537] Smith, "Racial Inequities."

[538] Ibid.

[539] Association of American Medical Colleges, "Meeting the Needs of Communities: Teaching Hospitals and Their Potentially Underserved Patient Populations," fact sheet, vol. 2, no. 9 (August 1998), accessed at <http: //www.aamc. org/about/progemph/camcam/factshts/vol2_no9.htm>.

patients.[540] With the shift toward managed care, and movement toward reductions in medicare spending, however, teaching hospitals are in particular jeopardy for losing much needed operational funds.[541]

Nursing Homes

Nursing homes are also a large segment of the Nation's health care industry. However, before the 20th century, nursing homes were virtually indistinguishable from hospitals. Voluntary and public hospitals provided most of the long-term care for indigents, while the more affluent elderly received in-home care.[542] Gradually, however, the facilities that offered acute and long-term care separated into hospitals and nursing homes. Medicaid offered reimbursements for indigent care, which spurred an increase in the number of nursing homes.[543] The nursing home industry by 1975 was characterized by corporate chains that took advantage of the economies of scale brought about by the increased standardization induced by medicaid regulations. In general, these institutions boasted more beds than hospitals.[544] In addition, the medicaid program paid more for indigent care in nursing homes than it did for acute care for indigents in hospitals. In 1995 public funds (overwhelmingly medicaid funds) accounted for 58 percent of all nursing home revenue.[545]

State governments were also apprehensive about ensuring title VI compliance by nursing homes, because of the increasing costs of medicaid.[546] Requiring nursing homes to admit more indigent and minority patients would increase State costs. Moreover, the failure of nursing homes to absorb these patients would usually result in a backlog of hospitalized patients on waiting lists. These patients would continue to be eligible for medicare while awaiting nursing home placement, which came directly from the Federal budget, easing the State medicaid budgets.[547]

As medicaid costs for long-term care increased, State medicaid agencies and nursing homes were in constant battles over medicaid funds. States fought to keep costs down, and nursing homes pushed for higher reimbursement rates.[548] After much debate, most States devised compromise plans with the nursing homes they regulated. Each plan was based on State control of the number of medicaid patients eligible for nursing home benefits, and nursing home control of admissions decisions. The States accomplished their end of the bargain through three methods: (1) restricting the number of nursing home beds, (2) reducing payments to the homes, and/or (3) restricting eligibility for medicaid benefits.[549]

Health Care Financing

Americans pay for health care primarily through health insurance. However, before World War II few people had health insurance. People received care at teaching hospitals or paid what they could to a physician when health care was needed.[550] By the 1940s, private insurance plans began to compete with Blue Cross and Blue Shield, which had been developed in the 1920s and 1930s in response to the Depression.[551] After World War II, Government price controls, unionization (and collectively bargained

[540] Rebecca Adams, "Teaching Hospitals Lobby to Block Medicare Cuts," *Congressional Quarterly Weekly*, May 15, 1999, p. 1149.

[541] *See* Ibid.

[542] Smith, *Health Care Divided*, p. 238.

[543] Ibid., p. 243

[544] Ibid., pp. 244–45.

[545] Ibid.

[546] Ibid., p. 249.

[547] Ibid.

[548] Ibid., pp. 252–53. Nursing homes rely on medicaid and other public funds for a substantial portion of their revenues. For example, in 1995 almost 60 percent of nursing home revenues nationally came from public funds. Ibid.

[549] Ibid. *See also* Gordon Bonnyman, managing attorney, Tennessee Justice Center, letter to Angel Hebert, Office of U.S. Representative Pete Stark, Sept. 10, 1997 (re: medicaid fraud and abuse in the nursing home industry) (citing the practice of limited bed certification). *See* USCCR, *The Health Care Challenge*, vol. II, chap. 3, for a discussion of the need for OCR policy guidance on nursing homes.

[550] Curtis P. McLaughlin, "Managed Care and Its Relationship to Public Health: Barriers and Opportunities," pp. 41–72 in Paul K. Halverson, Arnold D. Kaluzny, Curtis P. McLaughlin, and Glen P. Mays, *Managed Care and Public Health* (Gaithersburg, MD: Aspen Publishers, Inc., 1998), p. 43 (hereafter cited as McLaughlin, "Managed Care").

[551] Joseph A. Snoe, *American Health Care Delivery Systems* (St. Paul, MN: West Group, 1998), pp. 18–21 (hereafter cited as Snoe, *American Health Care Delivery Systems*). Blue Cross provided insurance for hospital services; Blue Shield provided for medical services. Ibid., p. 21

fringe benefits), and medical innovations (such as antibiotics) changed the way health providers and consumers related to one another.[552]

Today, financing for health care is provided by a number of entities. Employer-provided health plans cover some of the costs of health care; others rely on private health insurers, including managed care organizations, such as health maintenance organizations. However, other individuals, including those without insurance, must rely on financial assistance to obtain health coverage. Those who do not have health insurance may qualify for certain types of public assistance, such as supplementary security income (SSI).[553]

Private Insurance

Private insurance is often provided through managed care organizations. Generally, the term "managed care" describes a network of health service providers governed by rules that are designed to lower health care costs and provide greater access to health care. For example, most managed care organizations require their members to receive health services only from providers participating in the network and to work with a primary care physician who is required to make referrals to specialists, when needed.[554] Managed care organizations focus on coordination of services through a case manager, controlled access to services, and identification of treatment alternatives.[555] The American Medical Association (AMA) defines managed care as "processes and techniques used by any entity that delivers, administers, and/or assumes risk for health services in order to control or influence the quality, accessibility, utilization, costs and prices, or outcomes of such services provided to a defined population."[556]

Managed care systems include a variety of components, such as point of service arrangements, health maintenance organizations (HMOs), and preferred provider organizations. An HMO is a health plan that provides prepaid health care to members through designated providers.[557] Members pay a monthly payment as well as a deductible, copayment, or coinsurance at the time of services.[558] HMOs are often set up in the following ways: in the form of a group of physicians who provide all health services, by reliance on contracts with individual practice associations (IPAs), or a hybrid of the two.[559] Physicians usually are paid a fee for each patient enrolled in the plan, an arrangement known as capitation.[560] With an HMO, a physician serves as the primary care provider who must approve referrals to specialists.[561]

Similar to an HMO, preferred provider organizations (PPOs) provide health services to plan members (usually an employer or an insurance company) at discounted rates.[562] Financial incentives are provided for members to use health care providers who are under contract to the PPO.[563] Point of service plans permit members to use providers who are not within the plan network. Members pay a higher fee for such services.[564]

Enrollment in managed care plans has increased rapidly in the past 20 years. In 1976 there were 174 health plans with 6 million people (2.8 percent of the population) enrolled. By 1997 that number had increased to 651 plans with enrollment of almost 67 million people (25.2 percent of the population).[565] However, enrollment in HMOs varies across the country. Between 30 and 40 percent of the population in Connecticut, Delaware, the District of Columbia, Florida, Maryland, Minnesota, Missouri, New York, Pennsylvania, and Utah were enrolled in HMOs in 1997. Comparatively, in Alabama, Arkansas, Georgia, Idaho, Mississippi, Montana,

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[552] McLaughlin, "Managed Care," p. 43. *See also* Snoe, *American Health Care Delivery Systems*, chap. 1.

[553] NCHS, *Health, U.S., 1998*, p. 428. *See* "Public Insurance" below.

[554] Lourdes A. Rivera, Carolyn V. Brown, Lisa Handwerker, and Paula Ortiz, "What is Managed Care?" *Network News* (National Women's Health Network), vol. 22, no. 3 (May 1997), p. 1 (hereafter cited as Rivera et al., "What is Managed Care?").

[555] American Medical Association, "Principles of Managed Care," accessed at <http://www.ama-assn.org:80/advocacy/mgdcare/preface.htm>.

[556] Ibid.

[557] Snoe, *American Health Care Delivery Systems*, p. 361.

[558] NCHS, *Health, U.S., 1998*, p. 428.

[559] Ibid.

[560] Rivera et al., "What is Managed Care?" p. 1.

[561] Ibid.

[562] Snoe, *American Health Care Delivery Systems*, pp. 357–58.

[563] NCHS, *Health, U.S., 1998*, pp. 440–41.

[564] Rivera et al., "What is Managed Care?"

[565] NCHS, *Health, U.S., 1998*, p. 365.

North Dakota, South Dakota, West Virginia, and Wyoming, less than 10 percent of the population was enrolled in an HMO at that time.[566]

As enrollment in managed care organizations increases, policymakers have begun to examine managed care. Several bills are pending in Congress that would address consumers' concerns related to the administration of health plans.[567] Concern also has been expressed about the potential for managed care organizations to discriminate against individuals of certain groups.[568] Restrictions on service areas, enrollment, and formation of provider networks may restrict access to certain groups.[569] For example, plans often fail to include inner cities in their service areas, thereby excluding members of minority groups who may be concentrated in the inner city.[570] Others have noted that because managed care organizations are not fee-based but prepaid, there may be an incentive for managed care networks to lower costs by excluding those providers who treat more costly patients, resulting in discrimination against patients who have poorer health. According to one commentator:

> Doctors who serve poor and minority patients will not fare well in [a managed care] environment. When making decisions regarding the selection or dismissal of physicians, HMOs value cost-effectiveness in addition to medical quality. They value doctors who perform few procedures, order a low number of prescriptions, and minimize referrals. Because physicians serving poor and minority communities are faced with a high percentage of sick patients who necessarily demand a more intense and costly provision of services compared to a healthier groups of patients, these physicians, no matter how skilled and diligent, will appear to be less attractive to managed care groups as a result of the needs of the population that they serve. Therefore, managed care groups will not value physicians who treat poor and minority communities as highly as physicians who serve more affluent communities.[571]

Some commentators caution that as the health care system moves to a new form of organization—managed care—there may be incentives for discrimination.[572] One of the regional managers for HHS/OCR stated that the issue of managed care presents a challenge to civil rights enforcement in that many of the traditional civil rights issues are not applicable in a managed care setting.[573] According to one group of authors:

> [T]he very characteristic that gives managed care its power—the promise of care—also gives the system a powerful reason to discriminate against patients who are costly, difficult, and above all, undesirable. At their extreme, managed care plans' controls can result in the segregation of certain racially identifiable enrollee groups into health care systems that are less accessible and of poorer quality than are plans offered to other organization members. . . . these differentials in treatment may have no legitimate business basis.[574]

According to these authors, the characteristics of managed care may lead to discrimination. For example, managed care plans may limit their service areas to suburban areas, which tend to have a smaller percentage of minority residents than inner cities. Plans also can select which

566 Ibid., p. 378.

567 *See* Mary Agnes Carey and Sue Kirchoff, "GOP's Managed Care Bill Rushes Through House," *Congressional Quarterly Weekly*, July 25, 1998, pp. 2007–09; David Nather, "Fore Helps Senate Democrats Push GOP For Debate on Patients' Bill of Rights," *Daily Labor Report*, Aug. 3, 1998, p. A–9; "Clinton Threatens to Veto Republican Bills, Sets Tests for 'Real Patients' Bill of Rights'," *Daily Labor Report*, Aug. 11, 1998, p. A–8.

568 Sara Rosenbaum, Rafael Serrano, Michele Magar, and Gillian Stern, "Civil Rights in a Changing Health Care System," *Health Affairs*, vol. 16, no. 1 (January/February 1997), pp. 90–105 (hereafter cited as Rosenbaum et al., "Civil Rights in a Changing Health Care System"); *see also* Smith, "Racial Inequalities."

569 Under the Hill-Burton Act, a service area is defined as the geographic area designated by the facility in the most recent State plan approved by the Secretary under title VI of the Public Health Service Act. The term is often used loosely to refer to the geographic areas where the users of the facility reside. A hospital's service area is the geographical area from which the hospital draws, or is supposed to draw, the bulk of its inpatients. OCR, "Analysis of Civil Rights Data Training Workbook," p. 12.

570 Rosenbaum et al., "Civil Rights in a Changing Health Care System," p. 98.

571 "The Impact of Managed Care on Doctors Who Serve Poor and Minority Patients," *Harvard Law Review*, vol. 108 (May 1995), pp. 1628–29.

572 Geiger, "Race and Health Care," pp. 815–16; Rosenbaum, et al., "Civil Rights in a Changing Health Care System."

573 Ira Pollack, regional manager, Region IX, OCR, HHS, telephone interview, Feb. 17, 1999, p. 7.

574 Rosenbaum, et al., "Civil Rights in a Changing Health Care System," p. 96.

health services providers to contract with, potentially leaving out providers that have traditionally served the minority population.[575]

These authors state that there is evidence that managed care plans foster "segregated provider networks for both primary care and specialized services that cannot be explained by the residential location of the providers, the special skills or services of certain providers, or the special needs of patients."[576] For instance, managed care plans have been found to limit medicare enrollees to only certain providers in their networks of providers, essentially segregating the network. Similarly, minority physicians may find themselves receiving selected member assignments from the managed care plan. In other cases, managed care organizations have required member physicians to hold board certification, although many minority health care providers are not board certified.[577]

These authors note that "it is important to ensure that the new health care system does not perpetuate and deepen practices found in the old system."[578] To do this, the authors recommend that Federal and State agencies collect information on plan structures, care processes, and treatments for all groups served. The authors also suggest that the Federal Government provide State officials and officials in the health care industry guidance on the unlawful practices.[579]

Other criticisms of managed care plans come from enrollees who have complained that they have had problems getting permission from managed care plans to see medical specialists or pay emergency room bills, and they have no place to turn when a claim is denied.[580] Practices such as these have the potential to disproportionately affect low-income individuals who may be unable to pay for services denied by their managed care plan. Managed care plans have also been attacked for shortening patients' hospital stays in an effort to cut costs. In addition, customers have been denied important consumer information before enrolling, such as the background of network physicians and the level of satisfaction of current enrollees.[581]

Republicans and Democrats agree on broad principles for overhauling the managed care system, including greater protection for patients when dealing with their health plans. Proposed improvements would include better access to emergency care, greater choice in the selection of doctors, and the ability to appeal a health plan's denial of treatment.[582] However, the resulting "Healthcare Research and Quality Act of 1999," bill S. 326, which was approved by the Senate Health, Education, Labor, and Pensions Committee, does not provide comprehensive protection for all managed care plan enrollees.[583] The bill extends protection to the 48 million Americans who are insured through an employer, since these plans are exempt from State regulations, including patient protection laws.[584] The other 113 million Americans who are enrolled in managed care plans—including State employees, those who have independently purchased health insurance, and those whose jobs provide fully insured health coverage—are covered by State regulations, and will not be protected by S. 326.[585]

Public Insurance

As defined by NCHS, public assistance for health care takes the form of receipt of medicaid, medicare, Aid to Families with Dependent Children (AFDC), or supplemental security income (SSI).[586] Although the idea of a Government financed health insurance program has existed since the early 1900s,[587] it was not until the mid-1930s that legislation was enacted. In response

[575] Ibid., pp. 98–99.

[576] Ibid., p. 99.

[577] Ibid., pp. 98–99.

[578] Ibid., p. 101.

[579] Ibid., pp. 101–102. *See* USCCR, *The Health Care Challenge*, vol. II, chap. 3, for a discussion of the need for OCR policy guidance on managed care issues.

[580] Adriel Bettelheim, "Anxiety Over Health Care Quality," *Congressional Quarterly Outlook*, May 1, 1999, pp. 8–15.

[581] Ibid., p. 9.

[582] Karen Foerstel, "Debate on Managed Care Legislation Diverges Along Familiar Lines," *Congressional Quarterly Weekly*, Mar. 20, 1999, p. 701.

[583] S. 326, 106th Cong. (1999). This bill was approved 10–8, with all Republicans voting for it and all Democrats voting against it.

[584] Foerstel, "Debate on Managed Care," p. 702.

[585] Ibid.

[586] NCHS, *Health, U.S., 1998*, p. 428.

[587] HHS, Health Care Financing Administration, "Brief Summaries of Medicare and Medicaid," accessed at <http://www.hcfa.gov>.

to the social and economic pressure created by the Great Depression, President Franklin D. Roosevelt signed into law the Social Security Act of 1935.[588] This act implemented various programs for the general welfare, and it also created an old-age insurance program.[589] This legislation laid the foundation for the current medicare and medicaid programs, established in 1965.

Medicare provides health insurance coverage for persons aged 65 years and older, individuals with disabilities, and persons with permanent kidney failure.[590] Medicare provides health care coverage for more than 38 million people at a cost of approximately $200 billion.[591] Medicaid provides health care coverage for low-income individuals. It is administered by the States with matching funds from the Federal Government.[592] In fiscal year 1996, the medicaid program covered nearly 37 million people at a cost of approximately $163 billion. States have the option to cover other low-income persons and provide medical services not mandated by Federal law.[593] While medicaid rules and policies are set and monitored by Federal and State agencies, the administration of the programs is run by insurance companies, such as Blue Cross.[594] More recently, managed care organizations have become involved in medicaid and medicare.[595]

No Insurance

Those who are unemployed, work part time, or are retired often do not have adequate health insurance coverage. Most of the uninsured are minorities and women with children.[596] In 1985 the Consolidated Omnibus Budget Reconciliation Act (COBRA)[597] included provisions mandating health insurance companies to provide the option of continuing health insurance plan enrollment under a former employer's group health plan.[598] However, the COBRA does not require employers to offer discounted premiums to former employees as it does to current employees.[599]

Despite the option of COBRA coverage, many individuals remained without health insurance. In addition, the fear of losing insurance coverage because of preexisting conditions discouraged many people from changing jobs.[600] To remedy gaps in coverage caused by downsizing, layoffs, retirements, and job changes, Congress enacted the Health Insurance Portability and Accountability Act of 1996.[601] The act prohibits discrimination based on health status and guarantees access to group health insurance plans, regardless of certain preexisting conditions.[602]

Nonetheless, lack of health insurance continues to be a serious issue in the United States. A General Accounting Office (GAO) study found less than 40 percent of private employers offer health insurance to retirees (down from 60 to 70 percent in the 1980s).[603] Thus, 14 percent of those in the 55–64 age group do not have health insurance.[604] This is similar to the national av-

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[588] The Social Security Act of 1935, Pub. L. No. 74–271, ch. 531, 49 Stat. 620 (codified in scattered sections of 7, 11, 16, 22, 28, 39, 42, and 43 U.S.C. (1994 & Supp. III 1997)).

[589] HHS, Social Security Administration, "A Brief History of the Social Security Administration," accessed at <http://www.ssa.gov/history/pdf/histdev.pdf>.

[590] HHS, Health Care Financing Administration, "Overview of the Medicare Program," accessed at <http://www.hcfa.gov/medicare/careover.htm> (hereafter cited as HCFA, "Overview of Medicare").

[591] HHS, Health Care Financing Administration, fact sheet, February 1997, p. 1, accessed at <http://www.hcfa.gov/facts/1970b.htm> (hereafter cited as HCFA, Fact Sheet). Figures are for FY 1996.

[592] HCFA, "Overview of Medicare."

[593] HCFA, Fact Sheet, p. 2.

[594] Snoe, *American Health Care Delivery Systems*, p. 25.

[595] William J. Scanlon, director, Health Financing and Systems Issues, Health, Education, and Human Services Division, U.S. General Accounting Office, *Medicare Managed Care: HMO Rates, Other Factors Create Uneven Availability of Benefits*, testimony before the Special Committee on Aging, U.S. Senate, May 19, 1997 (GAO–T–HEHS–97–133), p. 2. *See also* Jon Hamilton, "Federal Largess Brigthens 1998 Medicaid Outlook," chap. 1 in *1998 Medicaid Managed Care Sourcebook: A Progress Report and Resource Guide on Managed Care Programs in the States* (New York: Faulkner & Gray, 1997).

[596] *See* NCHS, *Health, U.S., 1998*, pp. 361–62.

[597] Section 1867 of the Social Security Act, Aug. 14, 1935, Pub. L. No. 74–271, ch. 531, 49 Stat. 620, as amended by Pub. L. No. 99–272, § 9121 (b), 100 Stat. 227 (codified as amended at 29 U.S.C. §§ 1161–1168 (1994 & Supp. III 1997)).

[598] Snoe, *American Health Care Delivery Systems*, p. 80.

[599] Ibid., p. 81. In fact, employers may require the individual to pay up to 102 percent of the applicable premium. Ibid.

[600] Ibid., pp. 102–103.

[601] Pub. L. No. 104–191, title VI, § 601, 110 Stat. 1936 (codified at 42 U.S.C. §§ 300gg–300gg–92 (Supp. II 1996)).

[602] Snoe, American Health Care Delivery Systems, pp. 102–03.

[603] U.S. General Accounting Office, *Private Health Insurance: Declining Employer Coverage May Affect Access for 55- to 64-Year Olds*, GAO/HEHS–98–133, June 1998, p. 7.

[604] Ibid., p. 2.

erage for all ages. In 1994–95, 18 percent of adults aged 18 to 64 and 14 percent of children under age 18 did not have health insurance coverage.[605] Reasons for the decline in the number of persons with health insurance include rising costs for health care and decreases in family income and hourly wages. In addition, employers have increased the number of part-time and contract positions, which usually do not receive health benefits.[606]

Persons without health insurance are less likely to have a usual source of health care, receive preventive health care services, and have their health care needs met.[607] Lack of insurance, or insufficient coverage, also can result in inadequate care.[608] According to one study:

> Lack of health insurance is associated with lower health care access measures. Once uninsured persons enter the health care system, they are at greater risk of suffering medical injury as a result of substandard medical care. The lack of health insurance results in undesirable health care outcomes. Moreover, if the uninsured are a sicker population than their insured counterparts, then this imposes a more serious health problem because persons with the most need for health care are also the least likely to receive it.[609]

Indeed, studies have shown a relationship between receipt of health insurance and health status. One study found that persons with private insurance reported the best health, while those with public insurance reported the worst health.[610] Minorities and women are usually those who have public insurance or no insurance, resulting in unequal access to health care.[611]

Alarmingly, as private insurance increasingly comes under the control of managed care organizations, assistance to those without health insurance may disappear. An American Medical Association study estimates that doctors currently provide about $11 billion worth of free or discounted care annually.[612] However, according to a recent study in the *Journal of the American Medical Association*, as physicians become affiliated with managed care organizations and larger group practices, they "have less autonomy and control over the patients they see in practice arrangements that are more formal, centralized, and serve a defined population."[613] As a result, physicians have less latitude to provide charity care to members of the community who cannot afford health care.[614] A recent study of 12,000 physicians found that doctors whose income depends on managed care organizations devote, on average, 40 percent less time to charity care than doctors who are not involved in managed care.[615] According to one commentator:

> Charity care by physicians is eroding at the same time the dominant facilities that care for poor patients—the community clinics and public hospitals that traditionally have formed the nation's medical "safety net"—are themselves resting on increasingly shaky ground. In many communities around the country, those clinics and hospitals are less able to take care of their clientele of uninsured patients as they struggle to cope with changes in states' Medicaid programs and new limits on financial help from the federal government.[616]

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605 NCHS, *Health, U.S., 1998*, pp. 74, 124.

606 Paul Fronstin, Lawrence G. Goldberg, and Philip K. Robins, "An Analysis of the Decline in Private Health Insurance Coverage between 1988 and 1992," *Social Science Quarterly*, vol. 78, no. 1 (March 1997), pp. 62–63 (hereafter cited as Fronstin et al., "Decline in Private Health Insurance Coverage").

607 NCHS, *Health, U.S., 1998*, p. 124.

608 Fronstin et al., "Decline in Private Health Insurance Coverage," p. 45.

609 Treviño et al., "Health Care Access Among Mexican Americans," p. 113.

610 Beth Hahn and Ann Barry Flood, "No Insurance, Public Insurance, and Private Insurance: Do These Options Contribute to Differences in General Health?" *Journal of Health Care for the Poor and Underserved*, vol. 6, no. 1 (1995), pp. 55–57.

611 *See, e.g.*, Treviño et al., "Health Care Access Among Mexican Americans."

612 "43 Million Americans Now Uninsured," *Congressional Quarterly Outlook*, May 1, 1999, p. 22.

613 Peter J. Cunningham, Joy M. Grossman, Robert F. St. Peter, and Cara S. Lesser, "Managed Care and Physicians' Provision of Charity Care," *Journal of the American Medical Association*, vol. 281, no. 12 (Mar. 24/31, 1999), p. 1087.

614 Ibid., p. 1091.

615 "43 Million Americans Now Uninsured," p. 22.

616 Amy Goldstein, "Physicians Cutting Back Charity Work: Study Links Trend to Managed Care," *Washington Post*, Apr. 5, 1999, p. A–6.

Appendix 2.1
Age-adjusted Death Rates for Selected Causes of Death by Gender, Race, and Ethnicity, 1996

Cause of death	All persons	Male	Female	White	Black	American Indian/ Alaska Native	Asian/ Pacific Islander	Hispanic
All causes	491.6	623.7	381.0	466.8	738.3	456.7	277.4	365.9
Natural causes	440.6	547.2	354.8	419.2	662.3	374.5	250.3	316.9
Disease of the heart	134.5	178.8	98.2	129.8	191.5	100.8	71.7	88.6
Ischemic heart disease	86.7	119.3	60.4	86.4	99.4	63.8	44.8	58.2
Cerebrovascular diseases	26.4	28.5	24.6	24.5	44.2	21.1	23.9	19.5
Malignant neoplasms	127.9	153.8	108.8	125.2	167.8	84.9	76.3	77.8
Respiratory system	39.3	54.2	27.5	38.9	48.9	24.4	17.4	15.4
Colorectal	12.2	14.8	10.2	11.8	16.8	8.5	7.7	7.3
Prostate	14.9	14.9	N/A	13.5	33.8	9.8	5.8	9.9
Breast	20.2	N/A	20.2	19.8	26.5	12.7	8.9	12.8
Chronic obstructive pulmonary disease	21.0	25.9	17.6	21.5	17.8	12.6	8.6	8.9
Pneumonia and influenza	12.8	16.2	10.4	12.2	17.8	14.0	9.9	9.7
Chronic liver disease	7.5	10.7	4.5	7.3	9.2	20.7	2.6	12.6
Diabetes mellitus	13.6	14.9	12.5	12	28.8	27.8	8.8	18.8
Human immunodeficiency virus infection	11.1	18.1	4.2	7.2	41.4	4.2	2.2	16.3
External causes	50.9	76.5	26.2	47.5	76	82.1	27.1	49
Unintentional injuries	30.4	43.3	17.9	29.9	36.7	57.6	16.1	29
Motor vehicle-related injuries	16.2	22.3	10.2	16.3	16.7	34	9.5	16.1
Suicide	10.8	18	4	11.6	6.6	13	6	6.7
Homicide and legal intervention	8.5	13.3	3.6	4.9	30.6	10.1	4.6	12.4

SOURCE: U.S. Department of Health and Human Services, National Center for Health Statistics, *Health, United States, 1998 with Socioeconomic Status and Health Chartbook,* 1998, p. 203.

Appendix 2.2
Educational Attainment by Age, Race, and Hispanic Origin

Age, Race, Hispanic Origin (percentage of population)	Educational attainment			
	Less than 12 years	12 years	13-15 years	16 or more years
25-64 years of age				
All races	14.3	33.5	26.3	25.8
White, non-Hispanic	9.5	34.4	27.3	28.2
Asian or Pacific Islander	14.0	21.0	20.0	45.1
Black, non-Hispanic	20.3	37.1	27.9	14.8
Hispanic	44.3	27.1	18.9	9.7
65 years and over				
All races	35.1	34.0	17.0	13.9
White, non-Hispanic	31.0	36.1	18.1	14.8
Asian or Pacific Islander	37.2	27.1	15.3	19.8
Black, non-Hispanic	58.6	23.5	10.5	7.4
Hispanic	69.6	16.2	8.2	6.0

SOURCE: U.S. Department of Health and Human Services, National Center for Health Statistics, *Health, United States, 1998 with Socioeconomic Status and Health Chartbook,* 1998, p. 145.

Appendix 2.3
U.S. Resident Population by Race and Hispanic Origin, 1980–1995, and Projections 2000–2050

Year	Total	Hispanic	White	Black	American Indian/ Eskimo, Aleut	Asian/Pacific Islander
1980	226,546	6.0%	79.9%	11.5%	0.6%	1.1%
1985	237,924	7.7%	77.7%	11.7%	0.7%	2.2%
1990	248,765	9.0%	75.7%	11.8%	0.7%	2.8%
1995	262,761	10.4%	73.5%	12.0%	0.7%	3.3%
2000	271,237	11.2%	72.1%	12.3%	0.8%	3.7%
2005	276,990	12.1%	70.6%	12.5%	0.8%	4.0%
2010	281,468	13.0%	69.1%	12.7%	0.8%	4.3%
2015	285,472	14.0%	67.7%	12.9%	0.8%	4.6%
2020	288,807	15.0%	66.2%	13.1%	0.8%	4.9%
2030	291,070	17.1%	63.0%	13.5%	0.9%	5.6%
2040	287,685	19.5%	59.5%	13.8%	0.9%	6.3%
2050	282,524	22.0%	55.8%	14.2%	1.0%	7.0%

NOTE: Population totals are in thousands.

SOURCE: U.S. Department of Commerce, Economics and Statistics Administration, Bureau of the Census, *Statistical Abstract of the United States, 1998,* 118th edition, table 19.

Appendix 2.4
Profile of Dentists

	Race/Ethnicity of practitioner				
	White	Black	Hispanic	Asian	American Indian
Race/Ethnicity of patients					
White	76.6%	27.0%	43.6%	47.5%	62.7%
Black	10.5%	61.8%	9.8%	11.5%	10.0%
Hispanic	8.5%	7.9%	45.4%	14.5%	10.1%
Asian	3.2%	2.3%	3.0%	25.1%	8.5%
American Indian	1.4%	1.0%	1.1%	1.3%	10.3%
Total*	100.2%	100.0%	102.9%	99.9%	101.6%
Private dental practitioners providing free or reduced dental care to . . .					
HIV/AIDS patients	15.2%	27.1%	20.8%	18.6%	25.0%
Migrant workers	18.8%	19.6%	30.7%	24.1%	23.8%
Gross annual income of dental school graduates or enrollees					
Less than $100,000	38.5%	56.4%	52.1%	51.9%	42.3%
$100,000 or more	61.5%	43.7%	48.0%	48.1%	57.7%
Total*	100.0%	100.1%	100.1%	100.0%	100.0%
Current specialty areas of dental school graduates or enrollees					
General practitioners	79.9%	81.8%	82.1%	83.9%	82.7%
Specialists	18.4%	15.1%	16.5%	14.5%	15.5%
Not practicing	1.7%	3.1%	1.4%	1.5%	1.8%
Total*	100.0%	100.0%	100.0%	99.9%	100.0%

* Columns do not always total 100% because of rounding error and persons who identify themselves as having more than one race or ethnicity.

SOURCES: American Dental Association, "1996 Dentist Profile Survey: White Respondents," February 1998, tables 5 and 8, figures 6 and 11, pp. 6, 8, 12, 20; American Dental Association, "1996 Dentist Profile Survey: Black Respondents," February 1998, tables 6 and 9, figures 6 and 11, pp. 6, 8, 12, 20; American Dental Association, "1996 Dentist Profile Survey: Hispanic Respondents," February 1998, tables 6 and 9, figures 6 and 11, pp. 6, 8, 12, 20; American Dental Association, "1996 Dentist Profile Survey: Asian Respondents," March 1998, tables 6 and 9, figures 6 and 11, pp. 6, 8, 12, 20; American Dental Association, "1996 Dentist Profile Survey: American Indian Respondents," March 1998, tables 6 and 9, figures 5 and 8, pp. 6, 8, 11, 17.

Chapter 3

Gender, Race and Ethnicity: Experiences with Three Health Care Related Issues

To facilitate greater understanding of disparities based on race and gender within the health care system, it is helpful to look at the health experiences of minorities and women. These experiences reveal the importance of *vigorous* civil rights enforcement efforts applied to the Nation's health care system. Inequalities in access to quality health care can be observed in three broad contexts relating to health care: delivery of services, availability of financing, and appropriate research on health-related issues.

Access to Health Care

Despite civil rights legislation, equal treatment and equal access within the health care industry are not a reality for racial/ethnic minorities and women. Many barriers limit the quality of health care for these groups, including geographical distances, shortage of primary care providers in minority communities, and discrimination, both overt and subtle. According to one author, the factors that determine access to health care include:

> 1) need for health services, which includes variables such as perception of need, health status, risk for specific health conditions, and indications for preventive health services; 2) availability of specific services; 3) ability to obtain services, including ability to pay, opportunity to obtain services, and transportation to services; and 4) acceptability of the services, particularly in terms of language and cultural compatibility.[1]

The Department of Health and Human Services (HHS) has recognized the importance of increasing access to quality health care in its Healthy People 2010 objectives.[2] According to HHS:

> Having adequate access to health care services can significantly influence patient use of the health care system and, ultimately, improve health outcomes. Consequently, measures of access to care provide an important mechanism for evaluating the quality of the Nation's health care system. Limitations in access to care extend beyond such simple causes as a shortage of health care providers or facilities in some areas. Even where health care services are readily available, individuals may not have a usual source of care or may experience multiple barriers to receiving services, such as financial (e.g., lack of insurance or being underinsured), structural (e.g., lack of nearby facilities or service providers), and personal (e.g., cultural, language, knowledge barriers, physical barriers for the handicapped). In addition, populations with special needs, such as the disabled, elderly, chronically ill, and HIV infected, require access to providers with the requisite knowledge and skills to address their needs.[3]

Despite acknowledging disparities, HHS thus far has not sufficiently addressed the issue of access to quality health care for minorities and women. For example, racial and ethnic disparities and other civil rights issues are only indirectly addressed in HHS' discussion of access to health care. Although language and cultural barriers, and populations with special needs are mentioned, civil rights enforcement is not integrated into the goal of improving access and eliminating disparities.

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[1] Lillian Gonzalez-Pardo, "Women's Health Care: Limited Access Despite Majority Status," *Kansas Journal of Law and Public Policy*, fall 1993, pp. 57–62.

[2] U.S. Department of Health and Human Services (HHS), Office of Public Health and Science, *Healthy People 2010 Objectives: Draft for Public Comment*, Sept. 15, 1998, Access to Quality Health Services, p. 10–3 (stating as its goal to "improve access to comprehensive, high quality health care across a continuum of care") (hereafter cited as HHS, *Healthy People 2010 Objectives*).

[3] Ibid., Access to Quality Health Services, p. 10–4.

Race and Ethnicity

"The causes of these access and treatment differences are multifaceted and complex, but geography, culture and cultural insensitivity, racial stereotyping, the lack of minority health professionals, and institutional racism all factor into the causal equation."[4]

Members of racial and ethnic minority groups face multiple restrictions to health care delivery. From lack of insurance to lack of transportation, minorities are disproportionately affected by such barriers.[5] For example, it is sometimes difficult to take a day off of work to get health care services, find someone to care for one's children while in the hospital, or pay for services such as nursing homes.[6] Sometimes the existence of such barriers is perceived, but the effect is the same. Cultural barriers also exist in the form of misunderstood customs, the inability to express one's health needs, and lack of faith or trust in the health care system.[7] In addition, stereotypes cloud health care professionals' judgment in some cases, and mistrust impedes doctors and patients from effectively communicating with one another.[8] In other instances, discrimination and policies that result in a disparate impact on certain groups, and disparate treatment of individuals, further deteriorate the health care services available to and received by racial and ethnic minorities.[9]

In her remarks concerning the fiscal year 2000 budget, Secretary of Health and Human Services, Donna E. Shalala, stated:

> [T]oo many of our citizens face a higher risk of illness and death for only one reason: the color of their skin. For example, African-Americans have an infant mortality rate that remains more than twice that of Caucasians. And American Indians and Alaska Natives are more than three times as likely to die from diabetes, as are other Americans. . . . In this nation, being a member of a minority group shouldn't be hazardous to your health.[10]

From the perspective of the Commission's review of the HHS civil rights program, there seems to be more rhetoric than committed action to address this proclamation. Overall, HHS lacks a vigorous civil rights enforcement program, and the activities of OCR appear to have little impact on the agency as a whole.[11]

Discriminatory Policies and Practices

As a result of a history of discriminatory medical practices, many racial and ethnic minorities distrust the health care system. African Americans' distrust is rooted in slavery, Jim Crow laws, disenfranchisement, segregation, insufficient health care, and inappropriate scientific experimentation.[12] Many Hispanics perceive

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[4] Sidney Dean Watson, "Minority Access and Health Reform: A Civil Right to Health Care," *Journal of Law, Medicine and Ethics*, vol. 22, no. 2 (summer 1994), pp. 127–37.

[5] *See, e.g.*, Roni Rabin, "The Health Divide: With No Car, Care is a Big Challenge," *Newsday*, Dec. 2, 1998, p. A–78; Jane W. Peterson, Yvonne M. Sterling, and DeLois P. Weekes, "Access to Health Care: Perspectives of African American Families with Chronically Ill Children," *Family Community Health*, vol. 19, no. 4 (1997), p. 64 (hereafter cited as Peterson et al., "Access to Health Care").

[6] *See* Peterson et al., "Access to Health Care."

[7] Claudia L. Schur and Leigh Ann Albers, "Language, Sociodemographics, and Health Care Use of Hispanic Adults," *Journal of Health Care for the Poor and Underserved*, vol. 7, no. 2 (1996), p. 140; Sally Kohn, "Dismantling Sociocultural Barriers to Care," *Healthcare Forum Journal*, May/June 1995, pp. 30–33; Tracy A. Lieu, Paul W. Newacheck, and Margaret A. McManus, "Race, Ethnicity, and Access to Ambulatory Care among US Adolescents," *American Journal of Public Health*, vol. 83, no. 7 (July 1993), pp. 963–64 (hereafter cited as Lieu et al., "Race, Ethnicity, and Access").

[8] "End Racial Health-Care Inequities," *Newsday* editorial, Dec. 13, 1998, p. B–03; Ford Fessenden, "The Health Divide: a Difference of Life & Death: For Blacks, Medical Care and State of Health Trail Whites," *Newsday*, Nov. 29, 1998, p. A–04 (hereafter cited as Fessenden, "Difference of Life & Death").

[9] For example, policies on organ transplantation have a disparate impact on minorities. *See generally*, Ian Ayers, Laura G. Dooley, and Robert S. Gaston, "Unequal Racial Access to Kidney Transplantation," *Vanderbilt Law Review*, vol. 46 (May 1993), pp. 805–63. *See also* U.S. Commission on Civil Rights (USCCR), *The Health Care Challenge: Acknowledging Disparity, Confronting Discrimination, and Ensuring Equality, Vol. II. The Role of Federal Civil Rights Enforcement Efforts*, September 1999, chap. 3 (hereafter cited as USCCR, *The Health Care Challenge*, vol. II).

[10] Donna E. Shalala, Secretary, HHS, Remarks at the Fiscal Year 2000 Budget Press Conference, Washington, DC, Feb. 1, 1999, pp. 3–4.

[11] *See* USCCR, *The Health Care Challenge*, vol. II, chaps. 3–5, for a discussion of the organization of civil rights efforts and civil rights enforcement within HHS. *See also* USCCR, *The Health Care Challenge*, vol. II, chap. 1, for a discussion of the history of deficiencies within HHS' civil rights program.

[12] Vernellia R. Randall, "Does Clinton's Health Care Reform Proposal Ensure Equality of Health Care for Ethnic Americans and the Poor?" *Brooklyn Law Review*, vol. 60 (spring 1994), p. 206, n. 175 (hereafter cited as Randall, "Clinton's Health Care Reform Proposal").

providers in the current system as obstacles to receiving meaningful help; many Southeast Asians equate the health care system with death.[13] After years of neglect and culturally insensitive care, combined with discriminatory practices, it is no wonder that there is a deep mistrust of the health care system:

Obviously, a significant question is how this general distrust will be impacted by a system of health care designed to deny health care rather than to provide services. In particular, utilization review processes may allow providers to make decisions which will adversely impact persons of color more than European Americans. When that happens, some ethnic Americans' distrust in the health care system may be reaffirmed.[14]

HHS has the responsibility to address the fears and concerns of racial/ethnic minorities, and in particular to reexamine the discriminatory practices that have led to such fears. One attorney at HHS stated:

I think the first [recommendation] would be to try and address what I call the trust gap. There's a big disparity in health outcomes based on race, and the various parts of the Department [HHS] have tried to attack that in various ways. When the doctors come at it, they see it as a medical, scientific issue. They may not think about discrimination. They think they don't discriminate. They think their fellow colleagues are all bright and dedicated and don't discriminate. I think that the part that the Office for Civil Rights needs to address is the trust issue....There are surveys out there that basically say that African Americans don't trust medical personnel to do the right thing at the same rates that whites do, and there is anecdotal evidence that people, particularly African Americans, will go to the doctor later, they'll wait until they are really sick because, even more than everybody else, they don't regard the doctor as an inherently good thing.[15]

The policy and structural barriers that must be addressed are numerous and far reaching, because they have a significant effect on the ability to access quality health care for racial/ethnic minorities and women. A commentator, writing on legal issues of barriers to health care access for minorities, described a meeting of members of a public housing complex in New York held in the early 1990s.[16] The tenants met with attorneys retained in a race discrimination case against a New York hospital. The tenants, most of whom were members of minority groups, spoke about their experiences in receiving medical treatment at the nonprofit hospital nearby on which they relied for health care. The commentator described this meeting as follows:

Residents spoke of chaos in the emergency room of a not-for-profit hospital located nearby: One woman, Mrs. C., knew a neighbor who suffered with the effects of cancer and, yet, had lain in the emergency room for days. He was told that there was no bed for him. . . Mrs. C. also knew a young girl who went to the emergency room ill; after a wait, the girl was sent back home, where she died. . . .

Residents spoke of racial and economic segregation at the local not-for-profit: the hospital put the rich in one wing and the poor, including people with Medicaid, in another. The hospital's staff treated their two categories of patients differently. For example, the hospital would not move poor patients out of the emergency room into beds that were available in the "private" wing. Moreover, the conditions in the private and public wings contrasted sharply. The public wings, or poor people's wards, were "different worlds." Residents spoke of inferior food and a lack of privacy. They had seen feces in open areas. In the public ward, they stated, patients did not get their beds changed as often or often enough. In the public ward, patients did not get their medicine on time.

A young father of four, Mr. E., spoke about his stays in the public and private wings. In the public ward, his IV bag would empty and no one would change it until hours later. He watched other patients and learned how to shut off the IV himself. If a patient were in pain and asked for Tylenol, hospital staff would not give the patient the medication and, instead, would say that he had to wait until the next morning. In the private units, by contrast, appropriate medicines were listed on the charts and patients were able to get pain killers right away.

[13] Ibid.

[14] Ibid.

[15] George Lyon, associate general counsel, Office of General Counsel, Civil Rights Division, HHS, interview in Washington, DC, Dec. 22, 1998, pp. 15–16. Lyon further stated that he believed it was necessary for HHS to make sure that minority populations, in particular, are aware that there is an agency (OCR) to address discrimination in health care. Ibid.

[16] *See* Marianne L. Engleman Lado, "Breaking the Barriers of Access to Health Care: A Discussion of the Role of Civil Rights Litigation and the Relationship Between Burdens of Proof and the Experience of Denial," *Brooklyn Law Review*, vol. 60 (spring 1994), pp. 246–47.

Mr. S., who had also stayed on both wings, stated that physicians had different attitudes in the private wing and that nurses there provided more attention. Mr. S. stated that he felt badly when he left his bed in the private unit, because on his way out he had passed a number of poor people in need of beds—including someone with appendicitis. He knew that there were beds for insured people but not for the people he saw in the emergency room.[17]

The commentator who described this meeting observed that, for many years "private facilities have used specific, identifiable tactics to avoid treating poor people of color altogether or limiting their numbers."[18] She noted that some of the tactics are structural, meaning "designed to or with the effect of limiting access for the poor, and disproportionately, people of color."[19] Among these tactics are "[m]edical practices or facilities [that] are set up, or structured, so as to motivate barriers to entry."[20] She has written:

Such actions preclude the need for making further discriminatory determinations to exclude people of color on an individual basis. These structural decisions can sometimes be explained as motivated on another basis, but exclusion or change in patient "mix" is at least part of the reason for the action. . . .

For example, some facilities relocate from African-American or Latino communities to predominantly white, suburban communities.[21] Other facilities close or move the typical paths of entry for poor people—emergency and obstetrical care units. The privatization of public and not-for-profit health facilities is another technique for excluding the poor.[22] And still other facilities adopt restrictive hospital admissions policies, limit the size of their emergency room, or simply refuse to admit poor people of color as a general practice, "dumping" lower income patients on other facilities.[23] One survey conducted in Chicago showed that of patients transferred from emergency rooms at private hospitals to the local public hospital, a grossly disproportionate percentage were poor people of color.[24] Private nursing homes are particularly noteworthy for their exclusionary policies. They properly have been described as the most segregated of the country's publicly licensed health care facilities.[25]

Another author recounted the story of a black woman who discovered a lump in her breast:

When she went to a private hospital, she was denied treatment because she was indigent and her case was not considered an emergency. A public hospital performed a biopsy, which was positive, and gave her an appointment for treatment three weeks later. When Mrs. Kirchik arrived for treatment, however, the public hospital turned her away because she had not yet applied for Medicaid. Mrs. Kirchik tried another public hospital, but she was turned away because she was not a resident of the hospital's service area. When Mrs. Kirchik's story appeared in the newspaper, the first public hospital admitted her—to a private room—four months after she had first discovered the lump. Two weeks later, Mrs. Kirchik died.[26]

This author noted that the focus appears to be on the cost of health care, rather than on improving health status.

Inner-city residents, who are primarily minorities, have less access to quality health care than persons living in the suburbs, despite having more health problems.[27] According to the author:

Inner-city residents suffer from hypertension, heart disease, chronic bronchitis, emphysema, sight and hearing impairments, cancer, and congenital anomalies at a rate 50% higher than suburbanites. The rate of neurological and mental disorders in inner-city residents is nearly twice that of suburbanites.[28]

Inner-city residents also face far greater health hazards than suburban residents because of higher exposure to health hazards such as polluted air and water, crime, and drugs.[29]

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17 Ibid., p. 247, citing Meeting in Manhattan Residence Between Attorneys Retained in *Mussington v. St. Luke's Roosevelt Hospital Center* and Tenants of New York City Public Housing, Aug. 27, 1991 (Lado changed names for reasons of confidentiality).

18 Ibid., p. 248.

19 Ibid.

20 Ibid.

21 Ibid.

22 Ibid., p. 249 (internal cites omitted).

23 Ibid. (internal cites omitted).

24 Ibid. (internal cites omitted).

25 Ibid., pp. 249–50 (internal cites omitted).

26 Sidney D. Watson, "The Urban Crisis: The Kerner Commission Report Revisited: Health Care in the Inner City: Asking the Right Question," *North Carolina Law Review*, vol. 71 (June 1993), p. 1646 (hereafter cited as Watson, "Health Care in the Inner City").

27 Ibid., p. 1649.

28 Ibid., pp. 1648–49.

29 Ibid.

Discriminatory policies and practices, such as medical redlining, excessive wait times for care, unequal access to emergency care, and lack of continuity of care have a disparate impact on minorities. In other cases, overt discrimination and denial of quality health services endangers the lives of racial and ethnic minority patients. One author, citing several examples and studies of health care discrepancies, said, "Race discrimination is an almost salient yet pervasive problem in American health care."[30] The author identifies the following facially neutral policies and practices that disproportionately affect racial and ethnic minorities:

- Refusing to admit patients who do not have a physician with admitting privileges at that hospital.
- Requiring a deposit to treat a person in the emergency room or to admit a person for inpatient care.
- Refusing to deliver a baby if the mother has not received a specified amount of prenatal care.
- Excluding medicaid patients from hospitals and nursing homes.
- Failing to provide interpreters and translations of signs and forms for patients who do not speak English.
- Inquiring into a patient's citizenship, national origin, or immigration status before admitting that patient to the hospital.[31]

The author concludes, "Each of these polices operates to exclude a disproportionately large number of minorities. Each may foreclose access to health care if there are no alternative healthcare facilities in the area or may relegate minorities to second-class care if the only alternative is inferior."[32]

An example of an overtly discriminatory policy is California's Proposition 187, which prohibits people without legal residency status from obtaining any health care, other than emergency medical services, from publicly funded facilities.[33] The impact of Proposition 187 on immigrants and their children is potentially devastating, since most health care facilities in the State receive some public funding.[34]

After conducting a series of interviews about the potential effects of Proposition 187, researchers found that immigrant women's fears centered around the denial of services, costs for services, and threats of deportation. The researchers quoted several women who expressed concern with the law. For example, one immigrant woman said, "I'm afraid you'll go into a place and they won't help you or that we'll go to the hospital and they'll say, 'Hey, you go back to Mexico.' That makes one fearful."[35] Another respondent said, "They're not going to give us services, not us. If we don't qualify for MediCal, not even the children who are born here, they're not going to see us. And even if you're sick they won't give you medical care, so I think we are all going to infect each other. This affects me and my child. . . ."[36]

Other studies confirm that the passage of Proposition 187 affected immigrants' use of health services. For example:

> Half the directors of a representative sample of California primary care clinics serving low-income patients reported a decrease in the number of patient visits after the election. Directors of clinics serving a greater proportion of Latinos were significantly more likely to perceive a decrease in visits, particularly among those seeking prenatal and obstetric services. The decrease was reported to last for a median of seven weeks following the election. A time-series analysis showed a 26 percent decrease in the initia-

[30] Sidney D. Watson, "Reinvigorating Title VI: Defending Health Care Discrimination—It Shouldn't be so Easy," *Fordham Law Review*, vol. 58 (April 1990), p. 939.

[31] Ibid., pp. 941–92.

[32] Ibid., p. 942.

[33] 1994 CAL. LEGIS. SERV. Prop. 187 (Deering) (codified at CAL. EDUC. CODE §§ 48215(a) (Deering 1987 & Supp. 1999); CAL. HEALTH & SAFETY CODE § 130(a) (Deering 1990 & Supp. 1999); CAL. PENAL CODE §§ 113, 114 (Deering 1985 & Supp. 1999); CAL. PENAL CODE § 834b (Deering 1998); CAL. WELF. & INST. CODE § 10001.5 (Deering 1985 & Supp. 1999).

[34] Nancy Moss, Lisa Baumeister, and Judith Biewener, "Perspectives of Latina Immigrant Women on Proposition 187," *Journal of the American Medical Women's Association*, vol. 54, no. 4 (August/October 1996), pp. 161–65. Proposition 187 was overwhelming approved by voters (with 59 percent of the vote) in 1994. In March 1998, a U.S. district court granted a permanent injunction, enjoining the state from implementing and enforcing sections 4, 5, 6, 7, and 9 of Proposition 187. League of United Latin Am. Citizens v. Wilson, Case Nos. 94–7569, 94–7570, 94–7571, 94–7652, 95–0187, 1998 U.S. Dist. LEXIS 3368 (C.D. Cal. Mar. 13, 1998).

[35] Ibid., p. 163.

[36] Ibid., p. 164.

tion of outpatient mental health services by younger Hispanics at selected sites in San Francisco after the 1994 election. The decrease was associated with subsequent increase in use of crisis services.[37]

Immigrants, and particularly immigrant women, face considerable economic, legal, language, and cultural barriers to health care services.[38] Early entry into primary health care is one of the most effective ways to ensure positive health practices and early diagnosis of diseases, when they can be treated most effectively and inexpensively.[39] Statutes like Proposition 187 limit, and in some cases eliminate, access to care and have a resoundingly adverse effect on the health of immigrant communities. Despite Proposition 187's eventually being ruled partially unconstitutional, its overwhelming approval among voters reflects the strong anti-immigrant sentiment, particularly concerning issues of public assistance.[40]

The policies and practices cited here are just a few examples of the many that disproportionately disadvantage racial and ethnic minorities. It is often difficult to assess the effects of so-called facially neutral policies and practices. To eliminate these practices it is necessary to increase awareness among health care providers of the negative effect of standard discriminatory procedures.

One vehicle for achieving this is to incorporate standards for nondiscrimination into the accreditation process. Accreditation is the process by which facilities are certified as meeting the standards for providing quality health care, as determined by the accrediting organizations. HHS often relies on the accreditation status of facilities in determining eligibility for funding. Accreditation agencies, such as the Joint Commission on Accreditation of Healthcare Organizations (JCAHO), already recognize the importance of patients' rights, particularly for access to care. The JCAHO's standards for patient rights state that health care facilities must establish and maintain organizational structures that provide for the patient's right to reasonable access to care.[41] These standards must be taken a step further to address those policies that particularly affect minorities. Further, HHS must see to it that all accreditation standards for health care facilities receiving medicare, medicaid, and other Federal funding incorporate the facilities' responsibilities under Federal civil rights laws.

Inequities in Treatment and Services

"The subtle effects of racism still exist in our system. . . . Studies suggest that there is subtle, unconscious bias in the system. Health care professionals who believe that they are free of bias and free of prejudice, nevertheless can be shown indeed to be biased in their decision making in ways that they are not aware of."[42]

According to the Council on Ethical and Judicial Affairs of the American Medical Association (AMA), "Underlying the racial disparities in the quality of health among Americans are differences in both need and access."[43] According to the council, black persons are more likely to require health care services but are less likely to receive such services than are white persons. They are also less likely than whites to receive certain treatments or therapies. Racial disparities have been found in the likelihood of undergoing bypass surgery and receiving a kidney transplant and other life-saving procedures.[44]

[37] Ibid., p. 164–65.

[38] Francesca Gany and Heike De Bocanegra, "Overcoming Barriers to Improving the Health of Immigrant Women," *Journal of the American Medical Women's Association*, vol. 51, no. 4 (August/October 1996), pp. 155–60.

[39] Ibid., p. 155.

[40] *See* Victor C. Romero, "Broadening Our World: Citizens and Immigrants of Color in America," *Capital University Law Review*, vol. 27, no. 13 (1998), pp. 13–34; Berta Esperanza Hernandez-Truyol, "Building Bridges III: Personal Narratives, Incoherent Paradigms, and Plural Citizens," *Chicano-Latino Law Review*, vol. 19 (spring, 1998), pp. 303–29; Alison Fee, "Forbidding States From Providing Essential Social Services to Illegal Immigrants: The Constitutionality of Recent Federal Action," *Boston Public Interest Law Journal*, vol. 7 (winter 1998), pp. 93–115.

[41] Joint Commission on Accreditation of Healthcare Organizations (JCAHO), *1999 Hospital Accreditation Standards* (Oakbrook Terrace, IL: JCAHO, 1999), p. 50.

[42] Louis Sullivan, president, Morehouse School of Medicine, telephone interview, May 2, 1999, p. 8 (hereafter cited as Sullivan interview).

[43] American Medical Association, Council on Ethical and Judicial Affairs, "Black-White Disparities in Health Care," *Journal of the American Medical Association*, vol. 263, no. 17 (May 2, 1990), p. 2344 (hereafter cited as AMA, "Black-White Disparities")

[44] Ibid., pp. 2344–45.

One practice that has led to a disparity in health service delivery is kidney allocation to potential transplant recipients.[45] Currently, preference for available kidneys is given to recipients who are genetically compatible with the donor. This is determined by the antigens present in the cells.[46] Recipients with antigens similar to those of the donor are less likely than other recipients to reject the kidney. Because most kidney donors are white, most recipients with matching antigens are white as well. The wait for black kidney patients to receive a kidney transplant is twice as long as that for white patients. Further, white patients are 75 percent more likely to receive a transplant than black patients.[47] However, according to some commentators, mandated antigen matching is no longer necessary because of lower rejection rates in kidney transplants.[48]

Other commentators have written about racial and gender disparities in the treatment of emergency room patients complaining of chest pain.[49] These researchers found a statistically significant difference between the amount of time females and males waited to see a physician in the emergency room, with females waiting longer than males. Although the results were not statistically significant for the waiting time between black and white patients, a disproportionate number of both blacks and females reported waiting for more than an hour.[50]

The authors of this study concluded that previous differential access to medical care may cause a difference in emergency room wait times among blacks and whites, and males and females. Because white patients were more likely than black patients to have seen a private physician before going to the emergency room, their conditions may have been considered to be more serious than that of patients who had not previously seen a doctor.[51] The article states that intentional discrimination could not be a factor because the doctors represented both genders and different races, and because the physicians did not see the patients until they entered the examination room.[52] However, the authors did not take into account the admitting staff or other factors. Further, the authors state, "The current medical literature indicates that there is no data to justify the longer waiting times experienced by black and female patients in this study."[53] Absent medically sound reasons for such disparities among wait times, researchers need to focus attention on possible sources of discrimination.[54]

Many news reports have detailed the inequities confronting racial and ethnic minorities in the health care system. For example, a series of articles published in *Newsday* in November/December 1998 chronicled the disparities in health care on Long Island in New York.[55] After a year of analyzing hospital records and databases and researching health care in the region, reporters came to the following conclusions, many of which have been reached by other researchers:

- Compared with black patients, whites receive more advanced and intensive treatment.
- Blacks are more likely than whites to receive more radical, severe treatments, such as amputation.
- Blacks wait longer than whites for kidney transplants.
- Stereotypes about the treatment of minorities pervade the medical community.[56]

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[45] *See generally* Ayres et al., "Access to Kidney Transplantation." *See also* USCCR, *The Health Care Challenge,* vol. II, chap. 3.

[46] Ibid., pp. 807–08.

[47] Ibid., p. 808.

[48] Ibid., p. 811. *See also* Barbara A. Noah, "Racist Health Care?" *Florida Law Review*, vol. 48, pp. 362–65.

[49] *See* Chelmer L. Barrow, Jr., and Kirk A. Easley, "The Role of Gender and Race on the Time Delay for Emergency Department Patients Complaining of Chest Pain To Be Evaluated by a Physician," *Saint Louis University Public Law Review*, vol. 15 (1996), pp. 267–77.

[50] Ibid., p. 275.

[51] Ibid., p. 276.

[52] Ibid.

[53] Ibid.

[54] *See generally* Jackie Barrow, "Implications of the Emergency Medical Treatment and Active Labor Act (EMTALA) on Differences Based on Race and Gender in the Treatment of Patients Presenting to a Hospital Emergency Department with Chest Pain," *Saint Louis University Public Law Review*, vol. 15, no. 2 (1996), pp. 278–302.

[55] Fessenden, "Difference of Life & Death."

[56] Ibid. Other disparities noted in the *Newsday* series included: there appears to be feelings of distrust between black patients and white physicians; blacks are more likely than whites not only to be overweight and get less exercise, but they are also more likely to live in dangerous places and experience more stress; and whites live longer than blacks. Ibid.

The *Newsday* series provided several examples of diagnoses made on race-based assumptions. One article told of a doctor who informed a patient that although he had high blood pressure, it was not a problem because he was African American.[57] (High blood pressure is more common among African Americans, so the condition was accepted as "normal"). Another *Newsday* reporter retold the story of a black woman who was referred to an ophthalmologist for her blurred vision. The doctor assumed she was Asian because of her last name and when he found that she was black, he told her she was diabetic and had glaucoma. The patient, who was not diabetic, later had surgery for a nerve problem, not glaucoma. She felt she received poor care from the ophthalmologist who assumed she was diabetic because she was black and did not look for another explanation for her blurred vision.[58] Another article reported cases in which doctors assumed black patients with symptoms of sickle-cell disease were drug addicts and withheld the narcotic-grade drugs normally used to treat the disease.[59]

In a study of access to long-term care, researchers found that nonwhite patients experience longer delays than white patients in being placed in nursing homes.[60] Even after controlling for several factors, including patient age, gender, health conditions, special care requirements, behavior, financing, and cooperation of family, racial differences persisted in the wait time to be discharged from a hospital and placed in a nursing home, suggesting that nursing homes pair patients by race or "defer to the racial preferences of the patients" when assigning roommates.[61] The authors concluded, "The inescapable conclusion is that nursing homes discriminate on the basis of race in admitting patients. This practice is patently objectionable; it also is costly to hospitals, thus to society, since hospitals bear the direct costs of delayed discharges and hospitals do not keep costs to themselves."[62]

Another study found a statistically significant relationship between patient race and the services received in hospitals. Using regression analysis, the researchers found that nonwhite pneumonia patients received fewer hospital services than white patients. For example, nonwhite patients were less likely than whites to have necessary surgery. Such differences in the intensity of care were not explained by source of payment, health status, or location of hospital.[63]

Other studies have found discrepancies in the treatment of breast cancer. According to one author, minority women have higher death rates from cancer and/or receive less breast care than other groups.[64] For example, women in lower income groups are less likely to receive breast cancer information and screening. The author cites studies that indicate that black women receive different breast cancer treatments than white women; doctors are less likely to recommend breast cancer screening for Hispanic women; and breast cancer often is undetected and untreated in the Chinese American community.[65]

Researchers at the Health Care Financing Administration (HCFA), noting the disparities by race in the use of medicare services, studied the effects of race and income on the use of such services. These researchers found that black and low-income beneficiaries have fewer mammograms, influenza immunizations, and visits to physicians for ambulatory care. However, these groups have higher hospitalization rates, higher mortality rates, and greater instances of amputation.[66] In comparing mortality rates the re-

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[57] Ibid.

[58] Curtis L. Taylor, "Mistakes in the Past, Fears in the Present," *Newsday*, Dec. 4, 1998, p. A–08.

[59] Delthia Ricks, "Medical Myths: Black Patients Fight Against Harmful Silent Curriculum," *Newsday*, Dec. 6, 1998, p. A–04.

[60] David Falcone and Robert Broyles, "Access to Long-Term Care: Race as a Barrier," *Journal of Health Politics, Policy and Law*, vol. 19, no. 3 (fall 1994), p. 592.

[61] Ibid., p. 591.

[62] Ibid., p. 583.

[63] John Yergan, Ann Barry Flood, James P. LoGerfo, and Paula Diehr, "Relationship Between Patient Race and the Intensity of Hospital Services," *Medical Care*, vol. 25, no. 7 (July 1987), pp. 592, 600.

[64] Yolanda Vera, Kimberly Lee, and Amybeth Garcia-Bokor, "Breast Cancer and Poverty: Challenging Goliath with a Slingshot," *Clearinghouse Review*, May 1996, pp. 3–19 (hereafter cited as Vera et al., "Breast Cancer and Poverty").

[65] Ibid., p. 6.

[66] Marian E. Gornick, Paul W. Eggers, Thomas W. Reilly, Renee M. Mentnech, Leslye K. Fitterman, Lawrence E. Kucken, and Bruce C. Vladeck, "Effects of Race and Income on Mortality and Use of Services Among Medicare Beneficiaries," *New England Journal of Medicine*, vol. 335 (Sept. 12, 1996), pp. 791–99.

searchers found that black male medicare beneficiaries were 19 percent more likely to die (a mortality ratio of 1.19) than white male beneficiaries. For women, blacks were 16 percent more likely to die (a mortality ratio of 1.16).[67]

In addition, the authors noted that many black beneficiaries do not opt for many common elective surgical procedures, suggesting that "there may be barriers to elective surgical procedures for some groups of beneficiaries."[68] According to the authors, these results may indicate that black and low-income beneficiaries may receive less preventive care than other beneficiaries.[69] Thus, the authors concluded:

> The implementation of Medicare was necessary to provide access to care for the elderly. However, the differential patterns in the use of many specific services according to race and income indicate that the provision of health insurance alone does not suffice to promote effective patterns of use by all beneficiaries.[70]

In 1994 the Agency for Health Care Policy and Research (AHCPR) reported disparities in hospital treatments performed on black and white patients. Using data from the Hospital Cost and Utilization Project, AHCPR conducted a longitudinal study of 172 medical procedures.[71] The agency found that for 36 of the procedures, whites had higher procedure rates than blacks for at least 7 of the 8 years of the study. White patients received more procedures related to the circulatory and musculoskeletal systems than did blacks.[72] Further, more whites than blacks received coronary bypass, a rate of 71.6 per 100,000, compared with 21.7 per 100,000. In addition, white patients' procedure rate for arthroscopy was 83.1, compared with 42.4 for black patients.[73] In contrast, compared with whites, blacks received more procedures related to renal failure, abortion, and glaucoma. AHCPR data also showed that blacks were more likely than whites to receive an amputation of a lower extremity.[74]

A more recent study examined differences in doctors' recommendations concerning chest pain. The researchers attempted to control for all intervening variables by having similarly dressed actors use the same script in videotaped interviews, thus ensuring that information on the "patients," such as occupation, insurance status, and risk status, was consistent.[75] The taped interviews were provided to 720 doctors for their recommendations. The study results indicate that men and whites were the most likely patients to be referred for cardiac catheterization. The researchers concluded that "the race and sex of the patient influence the recommendations of physicians independently of other factors . . . [which] may suggest bias on the part of the physicians."[76] However, the authors stated that they could not identify the form of bias. According to the authors:

> Bias may represent overt prejudice on the part of physicians or, more likely, could be the result of subconscious perceptions rather than deliberate actions or thoughts. Subconscious bias occurs when a patient's membership in a target group automatically activates a cultural stereotype in the physician's memory regardless of the level of prejudice the physician has.[77]

The results of studies such as these lead other commentators to conclude that health care providers are "less aggressive" in their treatment of minorities.[78] According to one commentator:

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[67] Ibid., p. 793.

[68] Ibid., p. 798.

[69] Ibid.

[70] Ibid.

[71] HHS, Public Health Service, Agency for Health Care and Policy Research, *Trends in Hospital Procedures Performed on Black Patients and White Patients: 1980–1987*, Provider Studies Research Note 20, AHCPR Pub. No. 94–003 (April 1994), pp. 5–7 (hereafter cited as AHCPR, *Trends in Hospital Procedures).*

[72] Ibid., p. 9.

[73] Ibid., p. 14.

[74] Ibid., pp. 9, 14.

[75] Kevin A. Schulman, Jesse A. Berlin, William Harless, Jon F. Kerner, Shyrl Sistrunk, Bernard J. Gersh, Ross Dube, Christopher K. Taleghani, Jennifer E. Burke, Sankey Williams, John M. Eisenberg, Jose J. Escarce, and William Ayers, "The Effect of Race and Sex on Physicians' Recommendations for Cardiac Catheterization," *New England Journal of Medicine*, Feb. 25, 1999, pp. 340, 618–26 (hereafter cited as Schulman et al., "Effect of Race and Sex"). *See also* Avram Goldstein, "GU Study Finds Disparity in Heart Care," *Washington Post*, Feb. 25, 1999, p. A–1.

[76] Schulman et al., "Effect of Race and Sex."

[77] Ibid.

[78] Noah, "Racist Health Care?" p. 359.

Physicians' treatment decisions may reflect some unstated prejudices—negative or pessimistic assumptions about their African-American patients' family support networks, dietary practices, or adherence to recommended post-treatment care regimens. In this sense, unconscious racism may be one factor that perpetuates the cycle of poorer health among African-Americans when compared to the white population.[79]

Uneven Health Care Use

An indication of access problems is the lower rates of use of health services by racial and ethnic minorities. The low utilization rates could give the impression that there are fewer health problems among these populations, but studies have shown that factors such as barriers to care directly affect utilization rates for these populations.[80] Asian Americans in particular exhibit low use rates for health services. A study of Korean Americans in Chicago found that 49 percent of those surveyed did not have a regular source of medical care.[81] Even when lack of health insurance is not the main barrier to care, use patterns of Asian Americans are different. A San Diego study of Southeast Asians showed that despite the fact that 9 out of 10 had health coverage, 44.5 percent had never had a general checkup.[82]

The low use rates stem from several inequalities in treatment. In the words of one Vietnamese patient:

> People and staff at [the facility] treat me well and care about me, but because they do not have enough money and staff, I wait and wait from 8 in the morning to 6 o'clock in the afternoon. I wait for a translator, I wait for my appointment, I wait for my medications in the pharmacy. The waits drain so much of my energy, it has really discouraged me from getting health care, even though I really need it.[83]

Other studies have shown a significant difference in the number of doctor's office visits between whites and blacks. Such differences persist even after the researchers control for variables such as income, education, and insurance.[84] One study found unexplained racial disparities in health care delivery and health status even after controlling for race-related stress (measured with a series of questions to determine unfair treatment).[85] The authors noted that, compared with whites, African Americans reported lower levels of psychological well-being, higher rates of ill health, and more bed-days.[86]

There are also disparities in preventive care, with subpopulations lagging behind whites. HHS found that children who are members of racial/ethnic minority groups are immunized far less frequently than white children.[87] Prenatal care is one preventive measure that has been shown to reduce mortality. According to HHS, "Failure to receive prenatal care during the first trimester can cause missed opportunities to prevent irreversible damage and lifelong handicaps to the newborn."[88] In 1996, 82 percent of mothers received prenatal care in the first trimester of pregnancy. However, there were substantial variations among racial, ethnic, and socioeconomic groups, as shown in table 3.1. Eighty-nine percent of Japanese American and Cuban American expectant mothers received prenatal care in their first trimester of pregnancy; 84 percent of white expectant mothers received prenatal care in their first trimester of pregnancy.

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[79] Ibid., p. 361.

[80] Laurin Mayeno and Sherry M. Hirota, "Access to Health Care," pp. 347–75, in Nolan W. S. Zane, David T. Takeuchi, and Kathleen N.J. Young, eds., *Confronting Critical Health Issues of Asian and Pacific Islander Americans* (Thousand Oaks, CA: Sage Publications, no date), p. 358.

[81] Ibid.

[82] Ibid.

[83] California Commission for Economic Development, Asian Pacific Islander Health Coalition, *California Asian Health Issues in the 1990s*, public hearing, Apr. 20, 1990. Information was provided by Asian Health Services. *See* Sherry Hirota, executive director, Asian Health Services, Oakland, CA, letter to Mireille Zieseniss, USCCR, Jan. 7, 1999 (hereafter cited as Hirota letter).

[84] Rudy Fichtenbaum and Kwabena Gyimah-Brempong, "The Effects of Race on the Use of Physicians' Services," *International Journal of Health Services*, vol. 27, no. 1 (1997), pp. 140–41.

[85] David R. Williams, Yan Yu, and James S. Jackson, "Racial Differences in Physical and Mental Health," *Journal of Health Psychology*, vol. 2(3) (1997), pp. 335–51 (hereafter cited as Williams, et al., "Racial Differences").

[86] Ibid., p. 347.

[87] Jane Perkins, "Race Discrimination in America's Health Care System," *Clearinghouse Review*, special issue, 1993, pp. 372–73, citing HHS, Public Health Service, Health Resources and Services Administration, *Health Status of Minorities and Low-Income Groups: Third Edition*, 1991, pp. 42–43 (hereafter cited as HRSA, *Health Status of Minorities*).

[88] HRSA, *Health Status of Minorities*, p. 40.

American Indian and Alaska Native mothers were the least likely to receive prenatal care at 67.7 percent.[89]

Table 3.1
Prenatal Care for Live Births by Race and Ethnicity, 1980–1996

Race/Ethnicity	1980	1990	1996
White, non-Hispanic	79.2	79.2	84.0
Black, non-Hispanic	62.4	60.6	71.4
American Indian or Alaska Native	55.8	57.9	67.7
Asian or Pacific Islander	73.7	75.1	81.2
Chinese	82.6	81.3	86.8
Japanese	86.1	87.0	89.3
Filipino	77.3	77.1	82.5
Hawaiian or part Hawaiian	–	65.8	78.5
Other Asian or Pacific Islander	–	71.9	78.4
Hispanic	60.2	60.2	72.2
Mexican	59.6	57.8	70.7
Puerto Rican	55.1	63.5	75.0
Cuban	82.7	84.8	89.2
Central and South American	58.8	61.5	75.0
Other and unknown Hispanic	66.4	66.4	74.6

SOURCE: U.S. Department of Health and Human Services, National Center for Health Statistics, *Health, United States, 1998 with Socioeconomic Status and Health Chartbook*, 1998, p. 176

In a study of differences in health care access among adolescents, researchers found striking differences in the types of care received by white and minority patients. Minority adolescents had "markedly worse health status" and were less likely to use health care than white adolescents.[90] The study also found that minority adolescents lacked a usual source of care, which may affect their overall health status. The researchers concluded that although several other factors may affect differences in health status and access (such as a lack of minority physicians, long waiting times at clinics, and dissatisfaction with physicians), they "cannot rule out the possibility of discrimination in either institutional access or physician behavior."[91] Findings such as those illustrated above led one commentator to conclude:

With major confounding variables increasingly controlled and adjusted for, investigators tend to invoke unspecified cultural differences, undocumented patient preferences, or a lack of information about the need for care as reasons for the differences. The alternative explanation is racism—that is, racially discriminatory rationing by physicians and health care institutions. We do not yet know enough to make that charge definitively. Furthermore, if racism is involved it is unlikely to be overt or even conscious. . . . The answers we need are to questions that are at a more personal level. What choices are black patients and white patients actually offered by their physicians? What do they hear? Do their physicians make specific recommendations? Do the patients participate fully in the decision-making process? What criteria do physicians use in making these clinical judgments? Are they applied equitably, or are they subtly influenced by racial stereotyping on the part of time-pressured physicians, reinforced both by institutional attitudes and unwarranted assumptions about prevalences and outcomes?[92]

Further, although it is often acknowledged that differences in health care use rates exist, they are frequently dismissed as lack of *initiative* on the part of the minority patient and not the more probable reason which is lack of *choice*. One author states:

The more fragmented, less preventive, and episodic use of health care by blacks is translated as a lack of personal responsibility rather than as a reflection of the differences in the nature of the institutions providing care and their relationships with their patients. At least some of the reported differences in rates of drug addiction, sexually transmitted diseases, and possibly even infant mortality reflect differences in the screening and reporting practices of the settings in which care is provided to blacks as opposed to those catering to whites. Such screening and reporting is more likely to be a part of the standard operating procedures of the more urban clinic settings where blacks disproportionately receive their care. In effect, these differences in procedures amount to an institutionalized form of racial profiling.[93]

[89] Ibid., p. 176.

[90] Lieu et al., "Race, Ethnicity, and Access," p. 963.

[91] Ibid., p. 964.

[92] H. Jack Geiger, "Race and Health Care—An American Dilemma?" *New England Journal of Medicine*, vol. 335 (Sept. 12, 1996), pp. 815–16.

[93] David Barton Smith, *Health Care Divided: Race and Healing A Nation* (Ann Arbor, MI: University of Michigan Press, 1999), pp. 319–20.

Gender

"Women and men have unique medical problems and health care needs. At a time when there have been improvements in the health status of men, the health status of women does not appear to be improving, perhaps because of the long-held assumption that disease patterns for women are the same as those for men."[94]

Gender disparities in access to health care persist in this country. As demonstrated below, women and men often receive differing treatments for similar conditions, differ in health-related behaviors, and use health services differently. Further, women's health care issues are often neglected or misunderstood by health professionals, and available care may not always be appropriate. According to HHS:

> Gender appropriateness also plays a significant role in determining health outcomes, behaviors, use patterns, and attitudes within all age groups. Women often are the health care decisionmakers and caregivers in their communities. When provided with enabling services and health promotion and prevention information, they can make better health choices and better navigate the health care system to get the care they and their families need.[95]

Some commentators contend that decisions on what aspect of health to study, what symptoms to acknowledge, and who will receive life-saving treatments are not based on scientific merit alone, but on judgment of social worth.[96] Women all too often fall outside the scope of medical interests and are short changed in the delivery of medical services.

Inequities in Treatment

"[Gender bias] pervades medicine, beginning with medical school admissions and education, encompassing research facilities and medical journals, and culminating in how women are treated as patients in clinics, hospitals, and physicians' offices across the country."[97]

Gender bias extends to all areas of health care, but is perhaps most visible in the inequities with which women are treated as patients. The gender differences in medical utilization and treatments may be the result of gender-related biological differences that have been obscured by the exclusion of women from research, different expectations of medical care between men and women, or gender bias by health care providers.[98] Women tend to undergo more examinations, laboratory tests, and blood pressure checks than men, but are less likely to receive major diagnostic or therapeutic interventions.[99]

Many studies suggest that inequities in treatment continue to be a common occurrence in a variety of medical procedures. Some examples are: men are more likely than women to be referred for diagnostic testing for lung cancer even when the risk factors are equal; women in need of kidney dialysis are approximately 30 percent less likely than men to receive a transplant; men are 6.5 times more likely than women to be referred for cardiac catheterization; and physicians are twice as likely to attribute symptoms of heart disease in women to psychiatric and noncardiac causes.[100]

Heart disease is the number one cause of death among women, and women are 20 percent more likely than men to die of a heart attack.[101] Yet the misperception of heart disease as a predominantly male issue persists, resulting in

[94] Jennifer Haas, "The Cost of Being a Woman," *New England Journal of Medicine*, editorial, vol. 338 (June 4, 1998), pp. 1694–95.

[95] HHS, *Healthy People 2010 Objectives*, Educational and Community-Based Programs, p. 4–8.

[96] Eileen Nechas and Denise Foley, *Unequal Treatment: What You Don't Know About How Women are Mistreated by the Medical Community* (New York: Simon and Schuster, 1994), p. 14.

[97] Karen H. Rothenberg, "Gender Matters: Implications for Clinical Research and Women's Health Care," *Houston Law Review*, vol. 32 (winter, 1996), pp. 1210, citing Leslie Laurence and Beth Weinhouse, *Outrageous Practices: The Alarming Truth About How Medicine Mistreats Women* (New York: Ballantine Books, 1994).

[98] Peter Franks and Carolyn M. Clancy, "Physician Gender Bias in Clinical Decisionmaking: Screening for Cancer in Primary Care," *Medical Care*, vol. 31 no. 3 (1993), pp. 213–18, citing American Medical Association, Council on Ethical and Judicial Affairs, "Gender Disparities in Clinical Decision Making," *Journal of the American Medical Association*, vol. 266, no. 4 (July 24/31, 1991), p. 559 (hereafter cited as AMA, "Gender Disparities").

[99] Franks and Clancy, "Physician Gender Bias," pp. 213–18.

[100] Rothenberg, "Gender Matters," p. 1210.

[101] HHS, Agency for Health Care Policy and Research, "AHCPR Women's Health Highlights," accessed at <http://www.acphr.gov/research/women1.htm#new1>. *See also* app. 2.1.

misdiagnosis and often preventable mortality. For example:

Kathy O'Brien (not her real name), a forty-two year old smoker, had been experiencing chest pains on and off for about a year. Her father and two of her uncles had died of heart attacks when young. She went to a clinic in the rural area of northwest New Jersey where she lived, and the local doctors told her she probably had gallstones. When the pain got worse, she went back to the clinic, where they told her she'd have to have a sonogram of her gallbladder. She left without having it done. Instead, Kathy went home, collapsed from chest pain, and nearly died. She had suffered a massive heart attack and gone into cardiac arrest. Technically dead, she had to be defibrillated with electrical shocks on the way to the hospital. The following day she was transferred to a larger teaching hospital, where doctors did an angiogram and found a blockage in a major blood vessel. She recovered well. But why, wondered the cardiologists at the larger hospital, didn't anyone recognize heart disease in a heavy smoker with chest pain and a serious family history of death from heart attack?[102]

One study found that early mortality after myocardial infarction (heart attack) was at least 40 percent higher among women than men. Even after controlling for age (women tend to suffer from heart attacks at more advanced ages than men) excess mortality rates were approximately 20 percent more frequent in women.[103] The authors of this study further state that there is evidence that women are less likely to receive fibrinolytic therapy, in part because women are considered ineligible for such therapy since they tend to be older, suffer myocardial infarction later after the onset of symptoms, and have other coexisting conditions.[104] The researchers said that a tendency toward less aggressive management of myocardial infarction in women may be an explanation for some of the excess mortality observed among women.[105]

Researchers have also found that there are other heart disease therapies and treatments, including coronary angioplasty and revascularization procedures, that are less likely to be performed on female patients.[106] These differences in treatment rates have been attributed to several factors:

- Men may undergo more procedures than women if physicians view coronary heart disease as more severe among men because of their higher incidence of the disease (once coronary heart disease is clinically manifest, however, the case fatality rate for women exceeds that for men).
- The rates at which procedures are performed may be influenced by physicians' perceptions of gender-related differences in risk and efficacy.
- If clinical criteria or patients' preferences do not explain these differences in the use of procedures, they may represent a gender bias in the delivery of medical care.[107]

Thus, women may not have equivalent access to procedures even though the incidence of heart disease among women is increasing. Patterns of similar magnitude for gender differences are reported with other diseases, such as dialysis and kidney transplantation in patients with end-stage renal disease.[108]

In a study on whether utilization rates for treatments for HIV patients differ by gender, researchers found that women receive fewer medical care services than men. Women with AIDS receive fewer services than male intravenous drug users with AIDS, and asymptomatic women with HIV infection are less likely to receive AZT.[109] The study also found that there are indications that many HIV-infected women are not being diagnosed accurately and are at elevated risk of having a primary health care provider who knows little about HIV.[110]

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[102] Laurence and Weinhouse, *Outrageous Practices*, p. 85.

[103] Roberto Malacrida, Michele Genoni, Aldo Pietro Maggioni, Vito Spataro, Sarah Parish, Alison Palmer, Rory Collins, and Tiziano Moccetti, "A Comparison of Early Outcome of Acute Myocardial Infarction in Women and Men," *New England Journal of Medicine*, vol. 338 (Jan. 1, 1998), pp. 8–14.

[104] Ibid., p. 13.

[105] Ibid.

[106] John Z Ayanian and Arnold M. Epstein, "Differences in the Use of Procedures Between Women and Men Hospitalized for Coronary Heart Disease," *New England Journal of Medicine*, vol. 325 (July 25, 1991), pp. 221–25.

[107] Ibid., p. 225.

[108] Ibid.

[109] Fred J. Hellinger, "The Use of Health Services By Women With HIV Infection," Health Services Research, vol. 28, no. 5 (December 1993), p. 543.

[110] Ibid.

The difficulty women face accessing adequate health care is not limited to illnesses that affect both men and women. Rather, there is evidence that women often find it difficult to access quality health care related to gender-specific illnesses such as breast cancer. One story illustrates this problem:

When Lorraine Pace found the lump in her breast one day in 1991, her doctor told her not to worry, it was probably just scar tissue from a cyst she'd had removed a few years earlier. When nothing showed up on a mammogram, Pace was happy to let the subject drop. . . . Eight months later, on a flight from Florida back to New York, Pace struck up a conversation with the pleasant middle-aged man sitting next to her. He told her he was a mortician. . . . What he said next startled her even more: He was disturbed by all the young women he was being asked to bury—women who had died in their thirties and forties of breast cancer. The next day Pace made a beeline for her doctor's office. "You told me not to worry about the lump. I want it out." Certain the lesion was benign, her doctor performed the surgery on an outpatient basis using only local anesthesia. Fifteen minutes later he was standing in front of Pace telling her, "You have invasive breast cancer." Recuperating from her lumpectomy, . . . Pace received more bad news. The cancer had spread to her lymph nodes. She'd need radiation and chemotherapy.[111]

Because breast cancer is rare in young women, doctors tend to believe these women are not at risk. The stories of young women being discouraged from receiving preventive care are numerous:

After performing a routine Pap and pelvic, [Cass] Brown's doctor offhandedly said, "You don't need a breast exam, do you?" Brown was taken aback. She certainly wanted an exam, but if her doctor didn't think she needed one, who was she to argue? Who was she to tell a doctor how to do his job? Three weeks later Brown felt a lump above her breast on her chest wall. Although the mammogram showed a highly suspicious mass, the surgeon to whom Brown was referred didn't want to waste his time following it up. "Who ordered this mammogram?" he barked. "You're too young." By now, Brown was angry. So what if she was only thirty-two. She wanted to have a biopsy. It didn't matter that her surgeon disapproved, that only 25–30 percent of biopsies came back positive. She wanted to be sure. Brown remembers the day her surgeon called with the results. Uncomfortable and embarrassed, he couldn't choke out the word *cancer*. Instead, he said, "It's something that can be handled short of mastectomy." As if that were some kind of consolation. "Is it malignant?" Brown finally asked. "Yes, but you don't need a mastectomy." Brown was livid. "Everything about breast cancer is breast, breast, breast. The reason the emphasis is on the breast and not your life is because it's men who lose your breast." But for Brown the biggest fear was of the cancer, of death.[112]

Inequities in treatment are further fueled by the role of gender in the physician-patient relationship. Studies evaluating the relationship between the gender of the physician and the offering of gender-related diagnostic procedures, such as breast exams, Pap smears, and mammograms, have shown that gender bias does indeed exist. Women who reported having a male physician were less likely to receive these procedures than women who had a female physician.[113] Further, women physicians are more likely to exercise greater diligence in offering screening tests, and women patients are more likely to follow through with obtaining tests suggested by women physicians.[114] Because communication is fundamental to achieving the intended goals of health care, the relationship between the patient and provider is central to health care delivery.

Another study of more than 8,000 women found that 69 percent reported having a usual provider, but only 9.8 percent of those providers were women. The study concluded that women with male providers were less likely to receive screening for cancer in primary care, including such diagnostic procedures as Pap tests, and were less likely to report ever having a mammogram.[115] These findings are significant considering the much greater numbers of male doctors.

An additional symptom of gender bias is the way in which women's medical concerns are not taken as seriously as men's, if not trivialized altogether. In a recent study, one out of four women (compared with 12 percent of men) stated that they had been "talked down to" or treated like a child by their physician, and nearly one out of five women had been told that

[111] Laurence and Weinhouse, *Outrageous Practices*, pp. 111–12.

[112] Ibid., pp. 116–17.

[113] Rothenberg, "Gender Matters," pp. 1211–12.

[114] Ibid., p. 1212.

[115] Franks and Clancy, "Physician Gender Bias," pp. 216–17.

a reported condition was "all in your head."[116] Women's complaints are dismissed by doctors far too often. One study found that primary care physicians judged 65 percent of women's symptoms to be influenced by emotional factors and women's complaints were more than twice as likely as men's to be identified as psychosomatic.[117] Two authors provide the story of a woman whose health problems were not taken seriously by her physicians:

> Shortly after the birth of her first child, Patricia Niemin began experiencing a light fluttering sensation in her chest. Her doctor, a family practitioner, assured her that it was normal, that this happened to women all the time. During her second pregnancy, the palpitations disappeared, only to return less than a year after her son was born. Over the next five years, instead of having palpitations one to two times a day for a few seconds each, she had them almost constantly. . . . By 1980, almost ten years after the palpitations began, Niemin's resting heart rate had increased from a worrisome canter to a fast-and-furious gallop.
>
> Without running any tests, her doctor put her on digitalis. Although it slowed her racing heart, her family was not sold on the treatment. . . . Niemin consulted an internist who immediately took her off the digitalis and immediately hospitalized her for tests. . . . But all the tests came back negative. With nothing organically wrong, the hospital cardiologist questioned her about her home life. When Niemin said that she was in the middle of a divorce, she could almost see the light bulbs go off above her doctor's head. "Honey," he said, patting the back of her hand, "go home and take some stress out of your life." "Wait a minute," Niemin said. "I don't operate badly under stress. I enjoy certain kinds of stress." What's more . . . Niemin was happier than she'd been in more than ten years. She was under less—not more—stress. She'd been reading medical books and she had her own theories about what was wrong with her. "It's got to be my thyroid," she told her doctors. "Everything points to my thyroid." "No," she heard over and over again, "that's not possible."
>
> Over the next decade Niemin had accumulated a grab bag of strange symptoms. . . . By January 1993, at the age of 40, she had lost 30 pounds, her cheeks were hollow, and her skin had taken on a grayish deathlike pall. Hot all the time, and extremely fatigued, she couldn't walk from one room to another without gasping for breath. . . . The endocrinologist she consulted took one look at her and said, "I can tell you what's wrong with you. You've got a thyroid problem." Finally, some twenty years after her initial symptoms had appeared, Niemin's condition had a name. She had Graves' disease, a thyroid disorder that affects three women for every man. The chilling part of her story is that, had she gone much longer without treatment, she could have been courting a fatal heart attack.[118]

The tendency to dismiss women's health complaints stems from the belief that women are more emotional than men. In addition, because women do receive more health care services, are more concerned about their health, and tend to be more vocal about their medical problems, physicians often unfairly stereotype them as "overanxious" or "hysterical."[119] In general, women report greater communication problems with their physicians and are more likely to change physicians because they are dissatisfied (41 percent of all women and 27 percent of men) with service. According to one author:

> Women's roles and experiences within the health care system differ from those of men. Professional patterns of dominance not only mirror, but reinforce social expectations of men as knowledgeable authorities and of women as differential servants who follow but do not initiate treatment programs. The gender imbalance within health care structures encourages doctors to accept prevailing social attitudes about women and illness. In appropriating the authority to define what is normal and healthy for women, male professionals have ensured women's continuing dependency on them.[120]

Uneven Health Care Use

Men and women differ in health-related behaviors and the use of health care services. One study suggested several reasons for gender differences in health care use, noting that men and women have different attitudes on health and medical care.[121] Because women view doctor's

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[116] Rothenberg, "Gender Matters," p. 1213, citing The Commonwealth Fund, *Survey of Women's Health* (New York: The Commonwealth Fund, July 1993).

[117] Laurence and Weinhouse, *Outrageous Practices*, p. 259.

[118] Ibid., pp. 259–60.

[119] Ibid., pp. 261–62.

[120] Rothenberg, "Gender Matters," pp. 1216–17.

[121] Peter Franks, Martha R. Gold, and Carolyn M. Clancy, "Use of Care and Subsequent Mortality: The Importance of Gender," *Health Services Research*, vol. 31, no. 3 (August 1996), pp. 347–63 (hereafter cited as Franks, et al., "Use of Care and Subsequent Mortality").

visits and checkups as preventive measures, they are more likely than men to schedule such appointments. Men, however, are most likely to obtain a checkup when required by their job or insurer. The authors also found in their study that men were more likely to have had a recent checkup, although they did not tend to have a usual source of care.[122] Another reason for increased utilization rates among women may be that because women continue to have a dominant role in caring for children, arranging for the health care needs of children may bring women into contact with physicians more often than men, leading to increased opportunities for the use of health care services.[123]

Other studies have shown that although women receive more health care services overall (more physician visits per year and services per visit), there are differences in types of health care use by men and women.[124] Part of this is the result of necessary gynecological and obstetrical care. Obstetricians/gynecologists account for nearly one-third of all office visits to specialists by women between the ages of 18 and 44.[125] One-third of diagnostic procedures performed on women are related to reproductive health.[126] Because women rely on multiple caregivers, a key issue in improving the delivery of care for women is better coordination between providers, for example between a primary care practitioner and a gynecologist.[127]

Additionally, throughout their lives, women have more acute symptoms, chronic conditions, and short-term and long-term disabilities arising from health problems, even when excluding reproductive problems, which require greater use of the health care system.[128] This gap in utilization rates between men and women narrows with age. As women grow older, they require less reproductive care and more care from other physicians. Hospitalization rates for women over the age of 45 are lower than for their male counterparts, and women are consistently more likely to use outpatient care.[129] Further, as stated earlier, even when reporting the same type of illness or medical need, women receive more examinations, laboratory tests, blood pressure checks, drug prescriptions, and return visits than men. However, studies have shown that women have less access to certain diagnostic and therapeutic interventions, such as kidney dialysis and transplantation and catheterization for coronary bypass surgery. Biological differences between men and women do not necessarily explain gender disparities in disease rates, diagnoses, or treatment,[130] and thus do not necessarily explain differences in use of services.

Specific groups of women also show differences in utilization rates and patterns. For example, while Hispanic women are more likely than their male counterparts to have a regular source of care and use preventive services, the most frequent source of their care is the emergency room.[131] Access to health care for Hispanic women has often been defined in terms of socioeconomic status, education, and language rather than as an issue of ethnicity and gender. It is assumed that access to health care is affected primarily by the lack of health insurance. Further, while access may be a condition for using services, other issues affect the use of services and access itself.[132] Having access does not necessarily mean that individuals will use services. One study of poor Hispanic women showed that the convenience of and satisfaction with services were important in women's decision to seek care.[133]

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[122] Ibid.

[123] Cameron A. Mustard, Patricia Kaufert, Anita Kozyrskyj, and Teresa Mayer, "Sex Differences in the Use of Health Care Services," *New England Journal of Medicine*, vol. 338 (June 4, 1998), pp. 1678–83.

[124] AMA, "Gender Disparities," p. 559.

[125] Karen Scott Collins, Diane Rowland, Alina Salganicoff, and Elizabeth Chait, *Assessing and Improving Women's Health*, A Women's Health Report of the Women's Research and Education Institute (New York: The Commonwealth Fund, 1994), p. 33 (hereafter cited as Collins et al., *Assessing and Improving Women's Health*).

[126] Ibid., p. 41.

[127] Ibid.

[128] Gonzalez-Pardo, "Women's Health Care," p. 57.

[129] Collins et al., *Assessing and Improving Women's Health*, p. 34.

[130] AMA, "Gender Disparities," p. 560.

[131] Teresa C. Juarbe, "Access to Health Care for Hispanic Women: A Primary Health Care Perspective," *Nursing Outlook*, vol. 43 (1995), pp. 23–28.

[132] Ibid., p. 24.

[133] Ibid., citing S.E. Radecki and G.S. Bernstein, "Use of Clinic Versus Private Family Planning Care by Low-Income Women: Access, Cost and Patient Satisfaction," *American Journal of Public Health*, vol. 79 (1986) pp. 692–97.

Many Hispanic women who have special risk behaviors or who are at risk for developing certain diseases do not receive preventive health care. For example, researchers have speculated that the higher mortality rates of Hispanic women with hypertensive disease may be attributed to limited access to health care.[134] Decreased access to health care limits the possiblity of receiving primary, preventive, or curative care.

Neglect of Women's Health Issues

Several health issues unique to women receive differing attention in both the health care delivery and health research arenas. Gender-specific health issues, such as reproductive health and violence against women,[135] need to be recognized and addressed by health care practitioners.[136] According to a law professor at the University of Virginia, the women's movement of the 1960s criticized the health care industry charging that:

> The way medicine was practiced was often sexist and denied women autonomy and control over their bodies. The result, they said, was poor quality care, provided in a demeaning manner, which often reduced rather than improved the quality of women's lives. The medical profession, these groups also said, inappropriately medicalized social problems . . . [137]

Further, during this time, medical professionals ignored health problems that primarily affected women, and medical institutions lacked a female perspective, resulting in inadequate health care.[138] This lack of attention to women's issues has consequences for today's health care delivery and treatment.

According to one author, "The interpretation of standard indicators of gender differences in health is not . . . straightforward."[139] This author states:

> [T]here are a number of diseases for which etiology, disease presentation, or disease course differ for women and men. For example some STDs [sexually transmitted diseases] are asymptomatic in women and therefore may be detected and treated later than in men; consequently women are more likely than men to suffer long-term effects of these diseases, including pelvic inflammatory disease, reproductive problems, and infertility. AIDS manifests itself differently in women than in men, and the 1993 Centers for Disease Control's expanded definition of AIDS recognized such female symptoms as persistent vaginal yeast infections and invasive cervical cancer. Heart disease typically occurs about ten years later in women than in men, in part because of the protective effect of estrogen in premenopausal women; further

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[134] Juarbe, "Access to Health Care for Hispanic Women," p. 24.

[135] The term "violence against women" incorporates issues such as "domestic violence," "sexual abuse," and "violence against intimates." Domestic violence includes "a range of violent experiences that women may endure at any point during their lives," including: "[p]hysical and sexual abuse during childhood, partner (or domestic) violence, and elder abuse during adulthood." Women's Health Equity Campaign; Maine Department of Human Services, Bureau of Health, Division of Community and Family Health; and Maine Department of Mental Health, Mental Retardation and Substance Abuse Services, *Women's Health: A Maine Profile* (Augusta, ME: Medical Care Development, Inc., undated), p. 9 (hereafter cited as ME Dept. of Human Services, et al., *Women's Health*). The Department of Justice defines "violence against intimates" as "incidents of violence against a current or former spouse, boyfriend, or girlfriend." Bureau of Justice Statistics, *Violence by Intimates: Analysis of Data on Crimes by Current and Former Spouses, Boyfriends, and Girlfriends*, NCJ–167237, March 1998, p. 1 (hereafter cited as DOJ, *Violence Against Intimates*). Sexual assault can be defined as "any sexual act performed by one person on another without that person's consent. Important components of the definition include the use of threat or force, the inability of the victim to give appropriate consent, or both." Harriette L. Hampton, "Care of the Woman Who Has Been Raped," *New England Journal of Medicine*, vol. 332, no. 4 (Jan. 26, 1995), p. 439.

[136] *See, e.g.*, American Association of University Women, "Contraceptive Coverage in Insurance Plans," January 1999, p. 1 (hereafter cited as AAUW, "Contraceptive Coverage in Insurance Plans"); The Commonwealth Fund Commission on Women's Health, *Addressing Domestic Violence and Its Consequences* (New York: The Commonwealth Fund, February 1998). For example, the Commonwealth Fund notes that "domestic violence is both a crime and a public health problem," further, "[w]hile low-income, less educated urban women are at somewhat greater than average risk, domestic violence occurs in urban, rural, and suburban communities and affects women at all levels of income and education." Ibid., p. 3.

[137] Marc A. Rodwin, "Patient Accountability and Quality of Care: Lessons From Medical Consumerism and the Patients' Rights, Women's Health and Disability Rights Movements," American Journal of Law and Medicine, vol. 20 (1994), p. 157.

[138] Ibid. For example, between the 1940s and the 1970s, the drug diethylstilbestrol (DES) was prescribed to over 3 million women to prevent miscarriages, despite several studies that suggested it was ineffective. In the 1970s, it was discovered that women whose mothers had taken DES were at risk of developing a rare form of vaginal cancer during puberty. Nonetheless, NIH continued to fund studies of DES. Ibid.

[139] Carol S. Weisman, *Women's Health Care* (Baltimore, MD: The Johns Hopkins University Press, 1998), p. 99.

more, the first sign of heart disease in men is often a heart attack, whereas the first sign in women is often angina.[140]

According to this author, women's health care has been "fragmented" between reproductive and nonreproductive health. The consequences of this division of services for women include inefficient delivery of health care services to women, and access burdens, gaps, and redundancies.[141] Accordingly, "since no provider has been trained in, or is accountable for, care of the whole woman, important health problems—such as the health consequences of sexual abuse or domestic violence—have been neglected both in research and clinical practice."[142]

Domestic violence disproportionately affects women, and, until recently, has been overlooked to a large extent by medical practitioners. According to one expert, "Women are more likely than men to be victims of domestic violence and sexual abuse, and health consequences to women of these experiences are just beginning to be understood."[143] Statistics from the Department of Justice reveal that women are approximately 85 percent of the victims of violence against intimates.[144] According to the Maine Department of Human Services, Bureau of Health, the consequences of violence for women are "enormous."[145] Women who experience domestic violence are more likely than other women to have poor health, infrequently see a doctor, abuse drugs and alcohol, experience depression, and consider suicide.[146] Victims of sexual assault also suffer both physical and psychological harm:

Threats, intimidation, and other acts of mental cruelty are common. The predominant fear of most rape victims is that they will be killed. The assault is often followed by a "rape trauma syndrome." The short-term phase my last for hours or days and consists of the emotional shock, disbelief, and despair caused by a life-threatening event. The woman's outward response during this phase varies from emotional instability to a well-controlled behavior pattern. Common signs include somatic symptoms, eating and sleeping disturbances, and emotional reactions such as mood swings, anxiety and depressions. The long-term phase of the syndrome, during which the victim attempts to restructure her life and relationships, may last months or years.[147]

Despite the disturbing health consequences of domestic violence and sexual assault, such health problems are often overlooked or treated inappropriately. As a result, women who have experienced violence or abuse appear to have greater difficulty accessing health care than other women. More than one third of women who had experienced violence or abuse reported a time when they did not get needed care.[148] Researchers have charged that although health care providers are "in a unique position to detect abuse and offer help" (because many domestic violence abuse victims seek care in emergency rooms and other health care facilities), they "are often criticized for not detecting the abuse or for giving inappropriate care."[149] These authors note that although training on domestic violence has increased, there has been very little research done on the impact of domestic violence.[150]

Because domestic violence is an issue that disproportionately affects women, health practitioners must take care to ensure that such issues are not overlooked when providing care. As one expert explained:

[140] Ibid. (citations omitted).

[141] Ibid., p. 121.

[142] Ibid., pp. 121–22.

[143] Ibid., p. 99 (citations omitted).

[144] DOJ, *Violence by Intimates*, p. 1. DOJ reports that the highest incidence of intimate violence occurs among black women, women aged 16 to 24, low-income women, and women living in urban areas. Ibid., p. 11.

[145] ME Dept. of Human Services, *Women's Health*, p. 9.

[146] Ibid. *See also* The Commonwealth Fund, *Health Concerns Across A Woman's Lifespan; 1998 Survey of Women's Health*, (New York: The Commonwealth Fund, May 1999). The Commonwealth Fund's report also found that women's experience with violence may lead to behaviors that could put them at greater health risk: they are twice as likely to smoke and nearly 40 percent more likely to drink alcohol regularly than other women. Ibid., p. 9.

[147] Hampton, "Care of the Woman Who Has Been Raped," p. 439.

[148] Commonwealth Fund, *Health Concerns Across a Woman's Lifespan*, pp. 7–9.

[149] Daniel G. Saunders and Phillips Kindy, "Predictors of Physicians' Responses to Women Abuse: The Role of Gender, Background, and Brief Training," *Journal of General Internal Medicine*, vol. 8 (November 1993), p. 443.

[150] Ibid. These researchers found that, compared with male physicians, female physicians detected abuse earlier and were more likely to make a referral for additional services related to abuse. Ibid., p. 445.

An understanding of violence as a public health problem begins by differentiating our experience of violence in ways that support effective intervention and prevention strategies. When violence occurs among persons who are or have been social partners, women are injured and men perpetrate the assault in the vast majority of cases. Thus a consideration of gender is key to strategies to reduce or prevent this type of violence.[151]

This author further states:

Without a gender understanding of domestic violence, it seems reasonable to some that we might address the needs of adult women by adapting mandatory reporting by medical personnel to protective services as other medico-legal strategies used since the mid-1960s to address abuse of children and disabled.

In fact, the health system has established mandatory reporting and protective services for those who are not able to care for themselves. Children, the disabled, and the frail elderly for instance, are all dependent groups who either lack civil rights or who lack the capacity to exercise their civil rights. Women who are victims of domestic violence are socially adult, fully competent individuals; while they may not yet have full equality before the law, including equal protection, they are certainly capable of exercising their civil rights. And, most importantly, . . . they are participants in—not objects of—our medical care efforts.[152]

HHS has acknowledged the effect of domestic violence in its Healthy People 2010 objectives. HHS notes that in 1994, over 500,000 women went to hospital emergency rooms for injuries related to domestic violence, the victims of which "suffer physically and emotionally."[153] HHS recognizes the lack of research and information on this issue:

Because of the nature of intimate partner violence and sexual violence, the problems are difficult to study. Consequently much remains unknown about the factors that increase or decrease the likelihood that men will behave violently towards women, the factors that endanger or protect women from violence, and the physical and emotional consequences of such violence for women and their children.[154]

Health Care Financing

"Today, those who are not insured either must suffer needless pain or early death because health care costs too much or they must face financial disaster when stricken with a serious illness. A disproportionate number of those who live with these undesirable alternatives are minorities and women. Their plight cannot go unheeded."[155]

According to a 1998 survey, one of the most prevalent health care concerns of Americans is that they will not be able to afford health insurance if costs continue to rise.[156] Although there is some debate over the reasons for the high costs of health care, there is agreement that one of the main causes is new medical technology. As technology improves not only do the costs of service rise, but people live longer and in turn require extended health care services.[157] For most Americans health insurance coverage provides the means to overcome financial barriers to care. People who lack insurance are far less likely to receive adequate care.[158] Financing, thus, continues to remain a barrier to health care access. A former Secretary of HHS cites lack of health insurance as the greatest challenge to access to health care for minorities:

[Lack of health insurance] really constitutes a significant barrier or impediment to getting health care. . . . [W]hat happens is that eventually people do get care who do not have insurance, but it is delayed. They often delay going to see a doctor or to an emergency room. When they do, the condition which they have is often more advanced and more difficult to treat. . . . It has a significant impact on not only people getting

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[151] Anne H. Flitcraft, "Clinical Violence Intervention: Lessons from Battered Women," *Journal of Health Care for the Poor and Underserved*, vol. 6, no. 2 (1995), p. 188.

[152] Ibid., pp. 424–25.

[153] HHS, *Healthy People 2010 Objectives*, Injury/Violence Prevention, p. 7–23.

[154] Ibid., p. 7–24.

[155] USCCR, *Health Insurance: Coverage and Employment Opportunities for Minorities and Women*, 1982.

[156] Louis Harris and Associates, *The Future of Health Care* (New York: Louis Harris and Associates for Baylor College of Medicine and Texas Children's Hospital, 1998).

[157] "Technology and Longer Lives Leading to Higher Health Bills," *USA Today Newsview*, Dec. 1998. The article also points out that although the elderly are living longer, they are not working longer, so there are more years of retirement (and thus health care) to finance.

[158] Collins et al., *Assessing and Improving Women's Health.*

care, but really the outcome of care when they do get it.[159]

According to the Agency for Health Care Policy and Research (ACHPR) in HHS, almost 13 million families (11.6 percent of all families) in the United States did not receive needed health care or had difficulty getting medical care in 1996.[160] The most common cause of this problem was the inability to afford health care. In addition, 18 percent of the U.S. population (46 million people) had no routine source of health care services.[161] Data from NCHS show that more than 15 percent of all men and women under age 65 have no form of health insurance.[162] In 1997 an estimated 43.4 million people were without any health insurance coverage during the entire calendar year.[163] Health care economists blame increasingly expensive premiums, cutbacks in employer coverage, and other cost pressures resulting from the changing health care industry.[164] However, additional factors increase an individual's likelihood of being uninsured.

According to the U.S. Department of Commerce, Economics and Statistics Administration, key factors related to not having health insurance include: (1) age—persons between 18 and 24 are most likely to be uninsured; (2) race and Hispanic origin—over 30 percent of Hispanics lack health insurance coverage; (3) educational attainment—the likelihood of being uninsured is inversely related to educational attainment; (4) work experience—the unemployed and those who work part time are more likely to be uninsured than those who work full time; (5) foreign birth—34.3 percent of the foreign-born population had no insurance coverage in 1997; (6) poverty—for each of the risk factors above, being poor increases the likelihood of not having health insurance.[165]

The number of persons who are uninsured varies greatly by State and region of the country. In 18 States, many in the southern half of the Nation, and the District of Columbia, more than 25 percent of the low-income population is uninsured, compared with 13 States with less than 20 percent of the low-income population uninsured[166] (see figure 3.1).

It is projected that the numbers of uninsured Americans will continue to grow. According to the Health Insurance Association of America, the number of uninsured Americans is likely to rise to more than one in five by the year 2007, even if good economic conditions continue.[167] The relationship between insurance premiums and income is the determinative factor in who has insurance. Six of 10 uninsured people have incomes below 200 percent of the poverty level.[168]

Health insurance coverage is an integral part of access to health care. Without insurance, individuals are not likely to receive appropriate health care. Numerous researchers have shown this to be the case:

> Persons without health insurance coverage often experience greater difficulty in obtaining access to health care, and lack of health care access leads to unfavorable health care outcomes. Moreover, if the uninsured happened to be a sicker population than the insured, then the problem magnifies and imposes a more serious health threat. . . . This paradox reflects the vexing health care situation in the United States that individuals at highest risk for medical illness are the individuals most likely to receive care.[169]

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159 Sullivan Interview, p. 6.

160 Office of Minority Health Resource Center, Office of Minority Health, HHS, "Access Problems Worsening," *Minority Health Update*, winter 1998, p. 1.

161 Ibid.

162 HHS, National Center for Health Statistics, *Health, United States, 1998 with Socioeconomic Status and Health Chartbook*, 1998, app. II, pp. 361–62 (hereafter cited as NCHS, *Health, U.S., 1998)*.

163 U.S. Department of Commerce, Economics and Statistics Administration, "Health Insurance Coverage: 1997," *Current Population Reports*, Sept. 1, 1998, pp. 2–4 (hereafter cited as Commerce, "Health Insurance Coverage"). Despite the medicaid program, 11.2 million poor people—nearly one-third of all poor people—were without health insurance in 1997. Ibid.

164 "43 Million Americans Now Uninsured," *Congressional Quarterly Outlook*, May 1, 1999, p. 22.

165 Commerce, "Health Insurance Coverage," pp. 2–4.

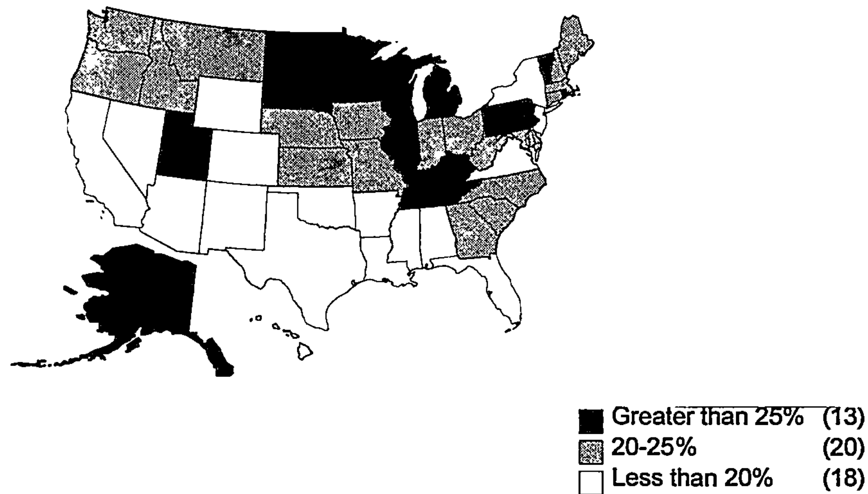
166 Henry J. Kaiser Family Foundation, Kaiser Commission on Medicaid and the Uninsured, "The Uninsured and Their Access to Health Care," *Uninsured Facts*, fact sheet, October 1998, p. 2.

167 "More than One in Five May Be Uninsured by 2007 Because of Mandates, HIAA Says," *Daily Labor Report*, Dec. 11, 1998, p. A–1.

168 Ibid.

169 Robert P. Treviño, Fernando M. Treviño, Rolando Medina, Gilbert Ramirez, and Robert R. Ramirez, "Health Care Access Among Mexican Americans with Different Health Insurance Coverage," *Journal of Health Care for the Poor and Underserved*, vol. 7, no. 2 (1996), p. 118.

Figure 3.1
Low-income Uninsured Population by State, 1994–1995



SOURCE: Henry J. Kaiser Family Foundation Commission on Medicaid and the Uninsured, "The Uninsured and Their Access to Health Care," Uninsured Facts, fact sheet, October 1998, p. 2.

Another author points to the problems in the health care financing system that lead to the provision of fewer health services for those who cannot afford insurance:

American businesses today pay drastically higher premiums than they once did and, ironically, provide less health care for their employees. State governments appropriate ever increasing amounts of money for what is now their first or second largest expenditure, the Medicaid program. More and more Americans are uninsured and hospitals complain that they can no longer bear the cost of treating increasing numbers of uninsured patients. Meanwhile, insurance companies are increasingly reluctant to underwrite the costs of care for the indigent.[170]

Yet another expert has stated:

Popular opinion assumes that inner-city residents without private insurance, Medicaid, or Medicare nonetheless find health care. We assume they may be inconvenienced by the form and location of the services, but that they still have access. Sadly, this is wrong. While emergency rooms in hospitals that accept Medicare are legally obliged to provide emergency services, other private health care providers have no such obligation. Long waiting lists for the few public services available to the uninsured poor mean that many either never obtain medical care or obtain care only when their condition is beyond treatment.[171]

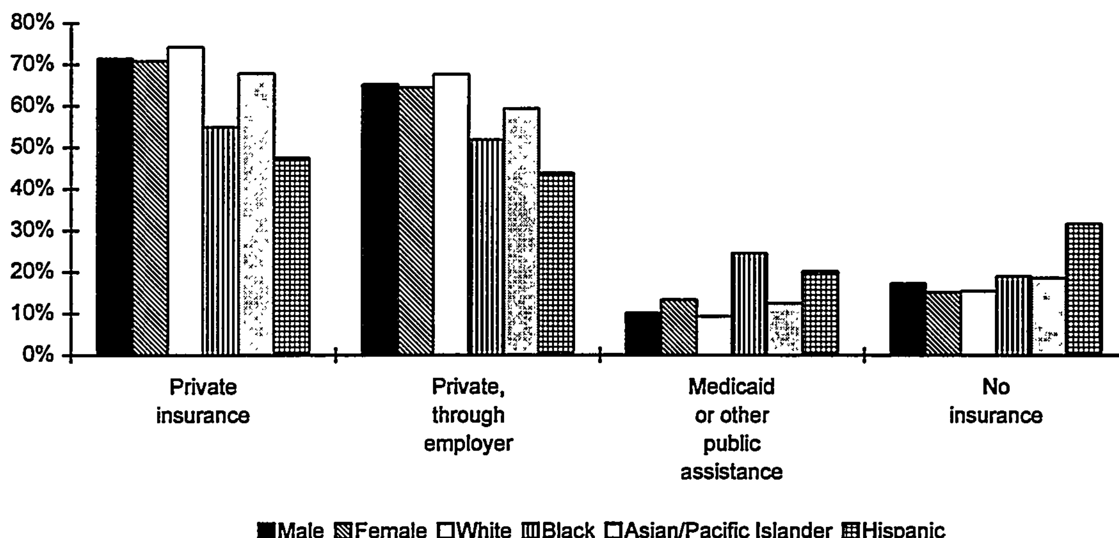
Figure 3.2 depicts health care coverage by gender, race, and ethnicity. Although similar percentages of men and women have private health insurance (71.4 and 70.8 percent, respectively), there are differences by race and ethnicity. Blacks and Hispanics are least likely to have private insurance. Only 54.9 percent of blacks and 47.5 percent of Hispanics have private insurance coverage, compared with 74.2 percent of whites and 67.8 percent of Asian Americans and Pacific Islanders.[172] This means that blacks and Hispanics are more likely to have no insurance

[170] Watson, "Health Care in the Inner City," p. 1654.

[171] Ibid.

[172] NCHS, *Health, U.S., 1998*, p. 361.

Figure 3.2
Health Care Coverage for Persons under Age 65, 1996



SOURCE: U.S. Department of Health and Human Service, National Center for Health Statistics, *Health, United States, 1998 with Socioeconomic Status and Health Chartbook*, 1998, pp. 361–62.

or to receive public insurance. Only 9.3 percent of the white population receives medicaid or another form of public health insurance; however, more than 20 percent of the black and Hispanic populations receive public health insurance. Women, as well, are slightly more likely than men to receive medicaid or other public assistance for health care (13.3 percent of women and 10.1 percent of men receive public assistance for health care).[173]

One recent study examined the effects of health care financing on the ability to obtain care. The researchers found that for each medical service in the study, medicaid enrollees are half as likely as uninsured persons and twice as likely as privately insured persons to report having difficulty obtaining services.[174] Uninsured individuals are most vulnerable. They often face difficulty receiving needed services in times of illness and accessing a regular source of care. More than 34 percent of the uninsured individuals in the study were unable to obtain the health services they believed they needed, compared with 22 percent of medicaid enrollees and 13 percent of individuals with private insurance.[175]

Research findings indicate that medicaid coverage has been effective in reducing some of the income-related differences in access to care; however, analogizing medicaid to private insurance ignores the differences in actual services rendered and the quality of care received.[176] While uninsured individuals obviously fare worse than medicaid enrollees in terms of access to care and utilization of care, the discrepancies between the predominantly minority and female public assistance recipients, and privately insured individuals cannot be ignored. Although medicaid improves access for those with more serious health problems, it does not provide the same level of care that private insurance provides.[177] Thus, it can be concluded that minorities and women are disproportionately more

[173] Ibid.

[174] Marc L. Berk and Claudia Schur, "Access to Care: How Much Difference Does Medicaid Make?" *Health Affairs*, May/June 1998, pp. 169–80.

[175] Ibid., pp. 172–73.

[176] Ibid., p. 177.

[177] Ibid.

likely to face less adequate care. Researchers have observed:

Race had a statistically significant effect on access for two of the three indicators. Non whites were almost 70 percent more likely than whites were to be unable to obtain medical care and had 10 percent more physician visits but had similar chances of having a usual source of care. The comparison between females and males is probably affected by unmeasured health status differences as well as by differences in health care behavior. Although women were twice as likely as men to have a usual source of care and had one-third more physician visits, they were still 50 percent more likely than men were to have unmet need for medical care.[178]

These findings indicate substantial variation across population subgroups as defined by source of medical coverage in the ability to obtain adequate health care.

Another limitation of public insurance as compared with private coverage is the amount of physician reimbursement for services. There is a significant gap between public and private reimbursement rates for services, with lower rates being given to physicians from medicare and medicaid than from private insurance companies. This may discourage physicians from seeing publicly covered patients, once again widening the access divide. It may also lessen the likelihood that providers will make referrals to specialists or provide care that is not covered by public insurance. Medicaid reimbursement rates, on the average, pay physicians less than 50 percent of what they would receive from private insurance reimbursements.[179]

In some cases, health insurance is available to those who are employed, although the type of health insurance and the quality and coverage of that insurance can vary by type and size of employer and the industry in which one works.[180] With rising health care costs, employers have sought cost-effective ways to continue providing health care benefits to their employees, for example by limiting eligibility for temporary, part-time, or new employees, or by reducing the financial protection of the health plan, increasing deductibles, or increasing the required employee contribution.[181] Small employers, which account for nearly 90 percent of firms in the United States, do not receive the volume discounts available to large ones in purchasing group plans and have even greater difficulty in providing affordable benefit plans.[182] By one report, employers of fewer than 200 people increased average employee premium contributions from 12 to 22 percent of the plan's cost for single-person coverage, and from 34 to 44 percent of the cost for family coverage, from 1988 to 1996.[183] Average family deductibles for conventional employer plans nearly doubled from $370 in 1988 to $668 in 1996 among these small employers.[184]

Furthermore, small employers are much less likely than larger firms to provide any insurance coverage. Surveys show that 91 to 96 percent of large employers offer insurance, but only 51 to 58 percent of businesses employing fewer than 50 workers offer health insurance to their workers.[185] One businesswoman described her difficulties in providing health insurance for her employees as follows:

In 1998, we carried health insurance with a large national insurer. Our monthly insurance premiums for 12 employees were extremely high; but [we] cov-

[178] Ibid., p. 176.

[179] Physician Payment Review Commission, *Annual Report to Congress*, 1994, p. 352.

[180] *See* Allyson G. Hall, Karen Scott Collins, and Sherry Glied, *Employer-Sponsored Health Insurance: Implications for Minority Workers* (New York: The Commonwealth Fund, February, 1999) (hereafter cited as Hall, et al., *Employer-Sponsored Health Insurance*). *See also* Mark V. Pauly, *Health Benefits at Work: An Economic and Political Analysis of Employment-Based Health Insurance* (Ann Arbor, MI: The University of Michigan Press, 1997), pp. 1–10.

[181] Jon Gabel, Kelly Hunt, and Jean Kim, KPMG Peat Marwick, LLP, "The Financial Burden of Self-Paid Health Insurance on the Poor and Near-Poor," published by the Commonwealth Fund, November 1997, pp. 2–3, accessed at <http://www.cmwf.org/ programs/insurance/Gabel251.asp> on July 21, 1999 (hereafter cited as KPMG Peat Marwick, "Financial Burden of Health Insurance").

[182] President's Advisory Commission on Consumer Protection and Quality in the Health Care Industry, "Quality First: Better Health Care for All Americans," Mar. 12, 1998, Chapter Six, accessed at <http://www.hcquality commission.gov/> (hereafter cited as Health Care Industry Advisory Commission, "Quality First").

[183] KPMG Peat Marwick, "Financial Burden of Health Insurance," citing J. Gabel, P. Ginsburg, and K. Hunt, "Small Employers and Their Health Benefits, 1988–1996: An Awkward Adolescence," *Health Affairs*, vol. 16, no. 5 (September/October 1997), pp. 103–10.

[184] Ibid.

[185] Health Care Industry Advisory Commission, "Quality First." *See also* Hall, et al., *Employer-Sponsored Health Insurance.*

ered 80 percent of all costs. . . . One day out of the clear blue, we received a call from the insurer that they were canceling our insurance due to the small number of people employed in the firm. We were all devastated and spent three months trying to find a firm that would insure the staff. This incident made it clear to me and my employees that something had to be done to assist small business owners in making insurance available at a reasonable cost without unfair and unjust cancellation.[186]

Note that the lost health care coverage was for the firm's 12 permanent employees. The company plan had not included coverage for the 1,000 temporary workers it employed during the year.[187]

According to one study, women-owned small businesses fared less well than other small businesses with respect to revenues, technology, and health care.[188] Women respondents were 20 percent less likely than other small business owners to provide health care benefits to employees.[189] Thus, employer-sponsored health insurance does not appear to provide comprehensive coverage for the Nation's employed population and minorities and women may bear the brunt of its inability to do so.

When small employers cannot or do not provide health coverage, minority workers are particularly hard hit. Only 38 to 48 percent of Blacks, Hispanics, Asian Americans, and other nonwhites working for employers with fewer than 100 employees have employer-based health insurance. Among firms with more than 100 workers, 61 to 75 percent of minorities have employer-sponsored insurance. In contrast, 63 percent of whites have insurance in small firms and 84 or more percent of them have it in large firms. Alternatively, among small employers' workers, 51 percent of Hispanics, 37 percent of blacks, 34 percent of Asian Americans or other nonwhites are uninsured. Only 20 percent of whites working for small employers are uninsured.[190]

Apart from the effects of small businesses on health coverage for minority workers, minority and female small business owners may have particular concerns about providing self and employee health insurance.[191] Between 1987 and 1992, the number of minority-owned small businesses increased by 60 percent, growing from 1.34 million to 2.15 million businesses nationwide. Of those minority-owned businesses, 39 percent are owned by Hispanics, 32 percent by African Americans, and 31 percent by Asian Americans.[192]

Recent media reports indicate that minority small business owners' optimism about profit growth in 1998 was tempered mainly by the rising costs of health care and other insurance.[193] Although minority-owned small businesses are increasing in number, these businesses often find it difficult to provide health care benefits for their employees, not including spouses and dependents.[194] In a 1997 Employee Health Benefits Survey, 50 percent of employers said that they did not offer benefits to their employees because it was too much of an administrative hassle, employees preferred higher wages, and they suffered from a high employee turnover rate.[195] Seventy-six percent of the uninsured surveyed in the 1997 California Behavioral Risk Factor Survey stated that the reason for their uninsured status was due to their employer not offering coverage.[196] Families headed by self-employed workers are also disadvantaged: only 24 percent of these families receive job based insurance, 28 percent buy their own

186 Terry Neese, CEO and founder, Terry Neese Personnel Services Oklahoma City, testimony before the Small Business Committee, U.S. House of Representatives, June 11, 1999. Ms. Neese is a former president of the National Association of Women Business Owners.

187 Ibid.

188 "In Brief," *Ethnic Newswatch*," vol. 14, no. 2 (Apr. 30, 1997), p. 50.

189 Ibid.

190 Hall et al., *Employer-Sponsored Health Insurance*, figure 7, table 2, and table A.1.

191 Sources on concerns of minority- and women-owned small business used in this report do not identify the race and sex of employees of such businesses.

192 Bob Dart, "Minority Owned Businesses on Rise, Census Bureau Says," Cox News Service, 1996, accessed at <http://www.latinolink.com>.

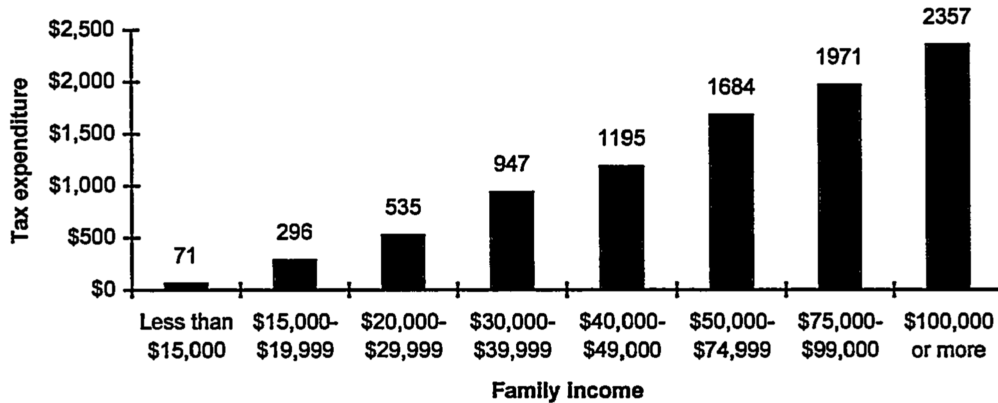
193 Stephen H. Dunphy, "The Newspaper," *Seattle Times*, Apr. 14, 1998, p. D–1; Jan Norman, "Capital Harder to Come by for Women's Firms," *Orange County Reporter*, Apr. 13, 1998, p. 17.

194 California Small Business Association, accessed at <http://www.csba.com>.

195 Schauffler and Brown, *The State of Health Insurance in California*.

196 Ibid.

Figure 3.3
Average Federal Health Benefits Tax Expenditure by Family Income, 1998



SOURCE: John Sheets and Paul Hogan, "Cost of Tax-Exempt Health Benefits in 1998," *Health Affairs*, vol. 18, no. 2, citing Lewin Group estimates using the Health Benefits Simulation Model.

Table 3.2
Family Health Care Expenditures by Income, 1992

Income level	Out of pocket expenses	Health care insurance premiums	Taxes on health care expenditures	Total expenditures	Percentage uninsured
Below $15,692	12.3%	6.4%	4.0%	22.6%	29.0%
$15,692–$29, 919	5.4%	5.9%	6.5%	17.8%	24.0%
$29,919–$46,705	3.7%	5.9%	7.6%	17.1%	13.0%
$46,705–$68,680	2.6%	5.3%	8.3%	16.2%	8.0%
$68,680–$117,666	2.0%	4.1%	8.8%	15.0%	6.0%
Above $117,666	1.5%	2.2%	10.8%	14.2%	5.0%
Average, all families	5.8%	5.6%	6.8%	18.2%	16.0%

SOURCE: Edith Rasell and Kainan Tang, "Paying for Health Care: Affordability and Equity in Proposals for Health Care Reform," working paper no. 11, Economic Policy Institute, December 1994, p. 7.

private plans, and 35 percent remain uninsured.[197]

Within ethnic minority-owned businesses, the number of uninsured employees is even greater than in nonminority-owned businesses. According to one report, Latinos (regardless of citizenship) and Asian and Pacific Islanders (noncitizens) are most likely to be uninsured due to lack of employer coverage, because they are more likely to work for an employer who offers no benefits.[198]

Even if employer-sponsored health insurance remains a viable means of coverage for some segments of the population, it may place an inordinate portion of the cost upon poor people. In the current system, employer-based health insurance is treated as a benefit; however, this benefit is not extended to all workers, nor is it without cost to employees when it is provided. It has been stated:

> While federal and state government, businesses, and insurance companies are intermediary payers, ultimately individuals and families pay all health care costs through some combination of out-of-pocket spending, insurance premiums, and federal, state, and local taxes. Even insurance premiums paid by

[197] Ibid.

[198] Ibid.

employers are, for the most part, offset by reductions in wages and salaries. Thus, while high health care costs cause problems for business and government, their greatest impact is on household budgets.[199]

As shown in figure 3.3, the employees' tax expenditure on wages that go toward health care is higher for high-income families.[200] Some researchers have argued that "the health benefits tax expenditure is disproportionately concentrated among higher income groups."[201] However, this position fails to acknowledge that the amount of money spent on taxes on health benefits represents a larger portion of the total income for those in the lower income levels. A report by the Congressional Budget Office confirms that individuals at the high end of the income scale realize far greater tax relief under the current employment-based health insurance system, while middle- and lower income workers benefit far less.[202] For example, as shown in table 3.2, research by the Economic Policy Institute indicates that in 1992, families in the lowest income range (earning less than $15,692 per year), spent 12.3 percent of their income on out-of-pocket expenses for health care. The percentage of income spent on out-of-pocket expenses for health care declined as income increased. For those families in the top income category (earning more than $117,666 per year), only 1.2 percent of their incomes were spent on out-of-pocket expenses.[203] When total expenditures for health care are considered, those in the lowest income groups spend a greater percentage of their incomes on health care expenditures.[204]

[199] Edith Rasell and Kainan Tang, "Paying for Health Care: Affordability and Equity in Proposals for Health Care Reform," working paper no. 11, Economic Policy Institute, December 1994.

[200] John Sheets and Paul Hogan, "Cost of Tax-Exempt Health Benefits in 1998," *Health Affairs*, vol. 18, no. 2, citing Lewin Group estimates using the Health Benefits Simulation Model.

[201] Ibid.

[202] John C. Liu, "What the CBO Says About the Tax Treatment of Employment-Based Health Insurance," *F.Y.I.*, Issue Report of The Heritage Foundation, May 25, 1994, p. 3, citing to Congressional Budget Office, "The Tax Treatment of Employment Based Health Insurance," March 1994, pp. xii–xiii.

[203] Rasell and Tang, "Paying for Health Care," p. 7.

[204] Ibid.

Race and Ethnicity

"A national health policy that conditions health care on the ability to pay will inevitably discriminate against racial minorities. As almost any school child knows, there is a strong correlation in America between race and poverty. Minorities are also much more likely to be represented among the ranks of the poor. Why, then, should we be surprised at racial disparities in access to [health] care? How could it be otherwise?"[205]

Inability to pay for health care services disproportionately strikes racial/ethnic minorities. According to the Commonwealth Fund:

> Historically, minorities as a group have been more likely to be uninsured. Although Medicaid has gone a long way to provide health insurance for those who would otherwise have no coverage, minorities continue to be disproportionately represented among the uninsured. This problem is partially attributable to the fact that members of minority groups are less likely to have employer-sponsored health insurance coverage, either because they have lower rates of employment or because they work in jobs and industries that do not provide coverage.[206]

According to these researchers, minorities are less likely than whites to have employer-provided health insurance. Even within the occupational categories that are most likely to have health insurance (full-time employment, employment for large employers, trade union members, and workers in the manufacturing industry and public administration), "minorities appear to be at a disadvantage in obtaining employer-sponsored health insurance."[207] Thus, "having a job does not equalize chances of obtaining health insurance coverage for minority workers" which "suggests barriers to being insured beyond employment or having an employer that offers health insurance benefits."[208]

As discussed above, minorities, particularly blacks and Hispanics, are more likely than

[205] Gordon Bonnyman, Jr., "Unmasking Jim Crow," *Journal of Health Politics, Policy, and Law*, vol. 18, no. 4 (winter 1993), p. 872 (citations omitted).

[206] Hall, et al., *Employer-Sponsored Health Insurance*, p. 1.

[207] Ibid., pp. 5–6.

[208] Ibid., p. 13. One such barrier may be out-of-pocket expenses related to health insurance. Ibid., p. 14.

whites to have no health insurance.[209] Of all racial and ethnic minorities, Korean Americans are the most likely to be uninsured.[210] Comparatively, whites are more likely to have private purchased health insurance or health insurance obtained through their employers. Blacks are least likely to have private insurance, but are more likely to receive medicaid or other public assistance for health care.[211]

Researchers have shown statistical disparities in both access to health care and health care financing for minorities. In one study, researchers found that lack of insurance and poverty are high predictors of low access to medical care. The researchers concluded that "neither the Medicaid program nor the reported physician surplus has solved the problem of access to medical care for the poor and minorities."[212] These authors noted that many adults do not qualify for medicaid, yet cannot afford private health insurance, and even if they can obtain insurance, they still do not have equal access to quality health care.[213]

Another study showed that minorities and low-income persons have less access to dental services than the general population. According to the authors, factors that account for this include cost of dental services, unavailability of dental insurance, and unwillingness of providers to provide uncompensated care.[214] Indeed, HHS has noted racial and ethnic disparities in the incidence of dental caries, an infectious disease that results in tooth decay.[215] According to HHS, "Almost all Americans have been affected by oral diseases; however, poor and low-income persons, members of racial and ethnic minority groups, and persons with little education are particularly at risk."[216]

The lack of health insurance among racial and ethnic minorities has a particularly adverse effect on children, with 22 percent of all poor and almost 23 percent of near-poor children not having any health insurance coverage. When broken down by race and ethnicity, Hispanic children fare worse than any other group. As table 3.3 shows, nearly 30 percent of Hispanic children from both poor and near-poor households do not have any form of health insurance.[217] According to the NCHS figures, children from near-poor (also known as working poor) families often are less likely than those from poor families to have any insurance coverage, in part because they may not qualify for public assistance.[218] In 1987, 66.7 percent of children were covered as dependents by employer-based insurance, however, by 1995 that figure had dropped to 58.6 percent.[219] The working poor are in a quandary—their employers often do not provide insurance, and they may earn too much to qualify for public assistance, yet not enough to be able to afford private insurance.

Public forms of health insurance fill some of the coverage gap. For example, to expand health coverage for uninsured children, the Children's Health Insurance Program (CHIP) was established in August 1997 as part of title IV of the Balanced Budget Act of 1997.[220] The CHIP law allocates $24 billion over 5 years to help States expand health insurance to children whose families earn too much to qualify for traditional medicaid, but not enough to afford private health insurance.[221] Under CHIP, the Federal

[209] *See* figure 3.2.

[210] Ignatius Bau, "We're Not All a Picture of Health," *Asian Week, The Voices of Asian Americans*, Feb. 18, 1999, p. 5.

[211] NCHS, *Health, U.S., 1998*, pp. 361–62. *See* figure 3.2.

[212] Rodney A. Hayward, Martin F. Shapiro, Howard E. Freeman, and Christopher R. Corey, "Inequities in Health Services Among Insured Americans: Do Working-Age Adults Have Less Access to Medical Care than the Elderly?" *New England Journal of Medicine*, vol. 318 (June 9, 1988), pp. 1507–12.

[213] Ibid.

[214] M. Ann Drum, D.W. Chen, and Rosemary E. Duffy, "Filling the Gap: Equity and Access to Oral Health Services for Minorities and the Underserved," *Family Medicine*, vol. 30, no. 3 (March 1998), p. 207.

[215] HHS, *Healthy People 2010 Objectives*, Oral Health, p. 9–5. According to HHS, "Americans cannot be truly healthy unless they are free from the burden of oral, dental, and craniofacial diseases and conditions." Ibid., p. 9–4.

[216] Ibid., p. 9–4.

[217] NCHS, *Health, U.S, 1998*, p. 150.

[218] Ibid.

[219] Carrie J. Gavora, "What To Do About Uninsured Children," *F.Y.I.*, Issue Report of The Heritage Foundation, no. 139 (Apr. 22, 1997), p. 3, citing Employee Benefit Research Institute, "Sources and Health Insurance and Characteristics of the Uninsured," issue brief no. 179 (November 1996).

[220] Pub. L. No. 105–33, §§ 4901, 4911–4913, 4921–4923, 111 Stat. 552–575 (codified at 42 U.S.C. §§ 1301, 1320a–7, 1396a, 1396b, 1396d, 1396r–1a, 1397aa, 1397bb, 1396a, 254c–2, 254c–3 (Supp. III 1997)).

[221] HHS, Health Care Financing Administration Press Office, "Children's Health Insurance Program Reaches 1998 Target," U.S. Newswire, Apr. 20, 1999 (hereafter cited as

Government will match State funds to enable States to initiate and expand health assistance to children whose family income is below 200 percent of the poverty line. The CHIP program gives States three options for covering uninsured children: designing a new children's health insurance program, expanding current medicaid programs, or a combination of the two strategies.[222] States must use at least 90 percent of the dispersed Federal funds for coverage plans and no more than 10 percent for administrative costs. As of April 1999, 52 CHIP plans had been approved by HHS.[223]

Table 3.3
Children's Health Insurance Coverage, 1994–1995

Race, Hispanic origin, and family income	Uninsured	Medicaid recipient	Private insurance
All races			
Poor	22.0	64.5	12.7
Near poor	22.8	18.1	55.5
Middle income	8.6	3.5	85.4
High income	4.2	1.4	93.4
White			
Poor	22.2	60.0	16.5
Near poor	21.0	14.5	60.8
Middle income	7.8	2.8	87.2
High income	3.8	1.1	94.3
Black			
Poor	14.6	74.3	10.5
Near poor	18.5	30.7	46.4
Middle income	8.4	7.7	79.2
High income	5.7	4.9	88.6
Hispanic Origin			
Poor	29.5	60.4	9.7
Near poor	32.7	21.6	43.4
Middle income	13.4	5.8	78.3
High income	7.2	3.0	88.2

SOURCE: U.S. Department of Health and Human Services, National Center for Health Statistics, *Health, United States, 1998 with Socioeconomic Status and Health Chartbook*, 1998, p. 150.

States participating in CHIP are required by Congress to submit annual reports and an evaluation of their programs to HHS in March 2000 in an effort to assess the effectiveness of CHIP in reducing the numbers of low-income uninsured children.[224] Although CHIP does not create universal coverage for all children, it has been praised as an opportunity to expand insurance coverage to a large portion of uninsured children,[225] and it has been cited as the most significant improvement in access to health care for children since the creation of medicaid.[226] In particular, according to the Children's Defense Fund, new children's insurance programs will benefit children from families employed by small businesses that do not offer health benefits.[227]

Nearly 1 million children in 43 States and U.S. territories obtained health insurance through CHIP in the program's first year of existence. However, in certain States, enrollment rates have been lower than anticipated.[228] For example, since the inception of the program, 330,000 children in California have been eligible for enrollment. As of July 1999, only 143,000 California children were enrolled.[229] Because eligibility for CHIP is based on financial status, many children who qualify are from racial and ethnic minorities; yet many children of immigrants, although eligible, may not be enrolled for several reasons, including fear of being declared a public charge, lack of culturally competent outreach, lack of linguistically appropriate materials, and the negative stigma associated with public health programs.[230]

HCFA, "Children's Health Insurance Program Reaches 1998 Target").

[222] Ibid.

[223] Ibid.

[224] Trish Riley, "How Will We Know if CHIP is Working?" *Health Affairs*, vol. 18, no. 2 (March/April 1999), pp. 64–66.

[225] American Academy of Pediatrics, Committee on Child Health Financing, "Principles of Child Health Care Financing," *Pediatrics*, vol. 102 (October 1998), pp. 994–95.

[226] HCFA, "Children's Health Insurance Program Reaches 1998 Target."

[227] Jack Elliot, "Health Groups Push for Expanded Insurance for Children," The Associated Press State and Local Wire, Mar. 24, 1999.

[228] Helen Schauffler and E. Richard Brown, *The State of Health Insurance in California, 1998* (The California Wellness Foundation, 1998), pp. 20–22.

[229] State of California, Managed Rick Medical Insurance Board, "Healthy Families Program Subscribers Enrolled by Ethnicity," accessed at <http://www.mrmib.ca.gov/MRMIB/HFP/HFPRpt3.html>. Of those children enrolled in California, 17.84 percent are white, 3.07 percent are black, 53.41 percent are Latino, .34 percent are American Indian, .01 percent are Alaska Native, and 14.86 percent are Asian American/Pacific Islander. Ibid.

[230] *See* Angie Wei, *Immigrant Rights State Policy Agenda* (Sacramento: CA Immigrant Welfare Collaborative, 1998); Kristen Hubbard, *Community Voices: Findings from the Child Health Insurance Feedback Loop on Efforts to Enroll*

For other uninsured individuals who qualify, including adults, public insurance is available in the form of medicaid and medicare. The percentage distribution of recipients of medicare and medicaid is shown in table 3.4.[231] In 1997, 85 percent of the medicare recipients were white, while Native Americans and Asian American/Pacific Islanders represented less than 1 percent of the recipients. Blacks were 9.0 percent of the recipients, and Hispanics were 1.1 percent of the recipients.[232] These numbers reflect, to some degree, the disparity in life expectancy among groups as well; that is, if a smaller percentage of blacks lives past the age of 65, then it would follow that they would make up a smaller proportion of the people receiving medicare.[233]

More minorities receive medicaid than medicare. As shown in table 3.4, whites were less than 50 percent of the medicaid recipients, while blacks accounted for almost one-quarter of the recipients. Another 17.5 percent of the recipients were Hispanic.[234] Native Americans accounted for under 1 percent of medicaid recipients, while Asian American/Pacific Islanders represented almost 2 percent of the medicaid recipients.[235] These percentages are congruent with the number of persons covered by private health insurance.[236]

Table 3.4
Medicare and Medicaid Recipients by Race/Ethnicity, 1997

Race/Ethnicity	Medicare*	Medicaid
White	85.4%	44.9%
Black	9.0%	24.1%
Native American	0.1%	0.8%
Asian/Pacific Islander	0.5%	1.9%
Hispanic	1.1%	17.5%
Unknown/other	4.0%	10.8%

* Percentages are for all medicare recipients, not just those over the age of 65.

SOURCE: U.S. Department of Health and Human Services, Health Care Financing Administration, "1997 HCFA Statistics," tables 3 and 13. Note: Numbers may not total 100 percent due to rounding.

Although older African Americans have access to medicare and medicaid, their access to quality health care remains limited because they usually do not have any supplementary health insurance. According to one author:

> Compared to older whites African Americans have poorer access to sophisticated diagnostic and treatment procedures and fewer physician visits, preventive health screenings, and general checkups. African-American elderly also use nursing homes less often than white elders. This stems from cultural factors and from such structural impediments as lower economic status and racial discrimination in nursing home placements.[237]

One health care expense specific to ethnic minorities that is often neglected is translation service. One commentator suggests that health plans often do little or nothing to make translation services available to non-English-speaking persons.[238] The author gives one example of how economic restrictions interact with language barriers:

> A patient must undergo a mastectomy and chooses the county hospital which has some form of transla-

Children in MediCal and Healthy Families (The 100% Campaign, 1998), p. 10; Dawn Horner, et al., *Reaching 100% of California's Children with Affordable Health Insurance: A Strategic Audit of Activities and Opportunities* (The Children's Partnership, 1998). *See also* discussion on immigrants' concerns with public assistance.

[231] Some of the differences in the percentages of medicare recipients is due to differences in the age distribution of various populations. For example, the Native American population is much younger than other racial/ethnic populations in the U.S. HHS, Indian Health Service, *1997 Trends in Indian Health*, p. 12 (hereafter cited as IHS, *1997 Trends in Indian Health*).

[232] HHS, Health Care Financing Administration, "1997 HCFA Statistics," tables 3 and 13 (hereafter cited as HCFA, "1997 Statistics").

[233] *See* chap. 2, figure 2.1.

[234] HCFA, "1997 Statistics."

[235] Ibid. Note that the Indian Health Service is the primary Federal health care provider for American Indians and Alaska Natives. IHS, *1997 Trends in Indian Health*, p. 1. *See also* USCCR, *The Health Care Challenge*, vol. II, chap. 5, for additional information on the Indian Health Service.

[236] *See* figure 3. 2.

[237] Stephen P. Wallace, Vilma Enriquez-Haas, and Kyriakos Markides, "The Consequences of Color-Blind Health Policy for Older Racial and Ethnic Minorities," *Stanford Law & Policy Review*, vol. 9 (spring 1998), p. 331 (citations omitted).

[238] Sherry M. Hirota, "Consumer and Community Interest Motivating Language Access," presented at the Henry J. Kaiser Family Foundation Forum, *Addressing Language Barriers to Health Care*, Sept. 18–19, 1995. *See* Hirota letter.

tion but would cost more as an out of plan hospital. A major source of concern and anxiety for the patient and her husband was having the delicate procedure performed without adequate communication. At the last minute, (within 24 hours of the operation) the commercial health plan informed the patient and referring physician that they will not pay for the mastectomy at a non-contracted hospital—that out of plan arrangements will only be made when "it involves a piece of equipment that can't be moved." Only when a Congressman and the State's Lieutenant Governor intervened, did the plan agree to pay their customary contracted rate to the hospital that was linguistically accessible.[239]

In addition to the economic barriers shared with other racial and ethnic minorities, immigrants face unique concerns in obtaining public assistance for health care. Many in immigrant communities are afraid of the health department because they equate it with the Immigration and Naturalization Service. They often fear that if they receive medicaid or other public health benefits, they will be considered a public charge which will affect their immigration status.[240] Although the use of public services alone is not grounds for exclusion, lack of knowledge among immigrants about this fact prevents many from seeking public health benefits.[241] The result is little or no use of either preventive or necessary medical care, resulting in poor health status. For example:

[I]n Illinois, a legal permanent resident mother of three citizen children went to the emergency room with strange heart palpitations and was given a battery of tests, for which she was billed thousands of dollars. She can't pay the bills and when she was advised to apply for Medicaid, she said she couldn't do that because she has applied for citizenship and at the naturalization workshop the applicants were told not to apply for pubic benefits. The immigrant is still very sick and needs more tests done but she can't afford them. Her daughter has had to stay at home from school many days to care for her.[242]

Immigrants' avoidance of health care and the erroneous equation of public health assistance with "public charge" also undermines the efforts to enroll even eligible children in health insurance programs. For example:

A ten year old child from Italy who was born with half a leg and half an arm, had outgrown her prosthesis and needed medical care immediately. The mother of the child, a naturalized citizen, refused available assistance because she was afraid it would jeopardize her children's citizenship and her husband's chances of becoming a permanent resident.[243]

Another report highlights this problem:

A citizen child in Boston, Massachusetts had to be rushed to the hospital by ambulance because the child went into convulsions. Subsequently it was determined the child needed on-going treatment. The child's mother, however, refused to fill out a Medicaid application on behalf of her child because she feared that she would not be permitted to adjust her immigration status if her child received Medicaid. Without Medicaid, the hospital will not be paid for the care it provided, and the child is unable to access medical treatment for his on-going health condition.[244]

In fact, compared with third and later generation children, immigrant children are three times as likely and second generation children are twice as likely to lack health insurance. Even among children whose parents work full time, year-round, those in immigrant families are less likely to be insured than those whose families were born in the United States.[245] The chilling effect of immigrants' fears is that in the long run the health of entire communities will be jeop-

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239 Hirota, "Consumer and Community Interest Motivating Language Access," p.1.

240 Immigrants who are seeking permanent residency or citizenship may be denied residency if they are considered by the INS to be potential "public charges." A public charge is an individual who relies on public assistance in the form of welfare, health insurance, and other social services. Use of public services alone is not grounds for denying residency; the INS uses overall evaluation of the applicant's status to determine whether he or she is a potential public charge. However, there is ambiguity in this area that prevents many immigrants from seeking public health benefits. Mayeno and Hirota, "Access to Health Care," p. 356.

241 Ibid.

242 Claudia Schlosberg and Dinah Wiley, *The Impact of INS Public Charge Determinations on Immigrant Access to Health Care*, A Report by the National Immigration Law Center and the National Health Law Program, May, 22, 1998, app. A.

243 Ibid.

244 Ibid.

245 Donald J. Hernandez and Evan Charney, eds., *From Generation to Generation: The Health and Well-Being of Children in Immigrant Families* (Washington, DC: National Academy Press, 1998), p. 10.

ardized. More money will be spent on emergency care, on the spread of untreated infections and communicable diseases, and in the treatment of prolonged or aggravated conditions that could have been prevented had early health care been received.[246]

Programs such as medicaid and medicare have been beneficial for many individuals. However, the development of public assistance has had a secondary effect of creating the potential for a new form of discrimination that particularly affects racial and ethnic minorities. Health care providers can substitute refusal of services based on method of payment for what was once refusal based on race or ethnicity. The racism may shift toward a more subtle form, but the effect is the same.[247] When minority patients who would otherwise not be able to afford health care have some means of payment, inequality of services and exclusion from treatment are less obvious, making acts of discrimination more difficult to identify.

Many economic proposals for improving access to health care are based on the premise that the primary barrier to health care is socioeconomic. While economic status is indeed an important factor in determining whether an individual will receive health care, it is not the only one. Economic proposals ignore the effect of other factors that can preclude an individual from receiving health services, such as race and racism. Race is a separate and independent barrier that affects not only a person's socioeconomic status, but the way he or she is treated as a patient. Further, when considering racial barriers, along with class and economic barriers, it should be recognized that the barriers will affect individuals within racial groups differently.[248]

> When institutional policies and practices have a discriminatory effect on the access of ethnic Americans to health care and a discriminatory effect on the quality of medical treatment, then racism is the problem. Any attempt to reform the health care system must provide mechanisms to remove racial barriers to health care. Proposals which focus on socioeconomic barriers will certainly improve access, but as universal coverage does not remove racial barriers, it is inadequate by itself.[249]

Gender

In 1978 a consultation held by the Commission found differences in health care coverage based on gender.[250] Twenty years later, although the gap has narrowed, discrepancies in types of coverage obtained by men and women persist. For example, in fiscal year 1997, approximately 36 percent of medicaid recipients were men and 58 percent were women[251] (see table 3.5).

Table 3.5
Medicare and Medicaid Recipients by Gender, 1997

Gender	Medicare	Medicaid
Male	42.9%	36.4%
Female	57.1%	57.9%
Unknown	0.0%	5.7%

SOURCE: U.S. Department of Health and Human Services, Health Care Financing Administration, "1997 HCFA Statistics," tables 3 and 13.

Because of their dependence on medicaid, women have overall lower uninsurance rates than men do; however, a significant number of women remain uninsured. One study found that, in 1998, one in four women under the age of 65 (21 million) were either uninsured at the time of the survey or had been uninsured at some point in the previous year.[252] Half of Hispanic women and one-third of African American and Asian American women reported having had no insurance at some point in the year before the study.[253] Since health insurance coverage is di-

[246] Schlosberg and Wiley, *The Impact of INS Public Charge Determinations.*

[247] Smith, *Health Care Divided,* p. 325.

[248] Randall, "Clinton's Health Care Reform Proposal," p. 215, citing Jose E. Becerra et al., "Infant Mortality Among Hispanics: A Portrait of Heterogeneity," *Journal of the American Medical Association,* vol. 265 (1991), p. 217.

[249] Randall, "Clinton's Health Care Reform Proposal," p. 215, citing Vernellia R. Randall, "Racist Health Care: Reforming the Health Care System to Meet the Needs of African Americans," *Health Matrix: Journal of Law and Medicine,* vol. 3 (1993), pp. 160–62.

[250] USCCR, Discrimination Against Minorities and Women in Pensions and Health, Life, and Disability Insurance, consultation held in Washington, DC, Apr. 24–26, 1978.

[251] HHS, Health Care Financing Administration, "1997 HCFA Statistics," table 13. The sex of 5.7 percent of the recipients was coded as "unknown."

[252] Commonwealth Fund, *Health Concerns Across a Woman's Lifespan,* p. 15.

[253] Ibid.

rectly related to income and poverty disproportionately affects minority women, they have high rates of uninsurance.

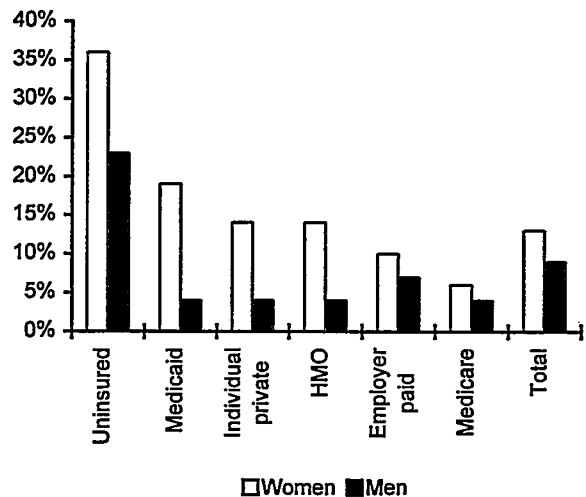
The connection between employment and insurance coverage has specific implications for women. Because women often have caregiving responsibilities for children or elderly parents, they are more likely than men to work part time, and are thus less likely to have insurance coverage through their jobs.[254] Some working women earn too little to buy private insurance, and yet often do not meet medicaid eligibility criteria. Working poor women are thus more likely to be uninsured than women who do not work.[255] Most women (83 percent) who have spent time uninsured are either working or married to a worker and living on low or modest income.[256]

Even women covered by private insurance are not immune to coverage disruptions. Equal numbers of men and women have employer-sponsored private insurance, but working women frequently obtain coverage through their husbands' employers.[257] Employed women who are covered through an employer-provided plan are twice as likely as men to have their coverage through a family member (usually a spouse) rather than through their own jobs.[258] This reliance on others makes women more susceptible than men to the loss of coverage through divorce, death of a spouse, or loss of job by a spouse. There is evidence that dependents have been particularly hard hit by the decline in employer-sponsored insurance in the last two decades and that employee costs for dependent coverage continue to increase.[259]

Women's lower overall uninsurance rate, as compared with men, is not necessarily an indication of better access to health care. The Commonwealth Fund Survey of Women's Health found that 13 percent of women, compared with 9 percent of men, did not receive needed health care.[260] Figure 3.4 shows the percentage distribution of men and women who stated that they did not receive necessary medical care in the year before the survey. More than one-third (36 percent) of all uninsured women did not receive care, compared with 23 percent of uninsured men. Uninsured women are also less likely to receive preventive care. Two of five uninsured women have not had a Pap test in the past year, and half of uninsured women do not have a regular doctor.[261]

Lack of private health insurance and dependence on public insurance among women also leads to uneven provision of services. One commentator points out that low-income women have difficulty obtaining medicaid coverage.

Figure 3.4
Percentage of Women and Men Who Did Not Receive Necessary Medical Care by Type of Insurance Coverage



SOURCE: The Commonwealth Fund, *The Commonwealth Fund Survey of Women's Health,* July 1993, p. 18.

[254] Collins et al., *Assessing and Improving Women's Health,* p. 37.

[255] Commonwealth Fund, *Health Care Reform: What is at Stake for Women?* Policy report of the Commonwealth Fund Commission on Women's Health (New York: Columbia University College of Physicians and Surgeons, July 1994), p. 6.

[256] Commonwealth Fund, *Health Concerns Across a Woman's Lifespan,* p. 16.

[257] Commonwealth Fund, *Health Care Reform,* p. 4.

[258] Collins et al., *Assessing and Improving Women's Health,* p. 37.

[259] Pamela Farley Short, "Gaps and Transitions in Health Insurance: What Are the Concerns of Women?" *Journal of Women's Health,* vol. 7, no. 6 (1998), pp. 725–37.

[260] The Commonwealth Fund, *The Health of American Women* (New York: Louis Harris and Associates, 1993).

[261] Commonwealth Fund, *Health Concerns Across a Woman's Lifespan,* p. 16. *See also* "Health Insurance Coverage and Access to Care for Working-Age Women," The Commonwealth Fund, fact sheet, May 1999.

However, even when medicaid coverage is available, many necessary services, including breast cancer examinations and mammograms, are not explicitly covered. Even when such services are made available, there are no requirements that medicaid or physicians provide periodic breast cancer screenings.[262]

A study by researchers at Harvard Medical School found that not only does the receipt of health services vary according to insurance coverage, but there is a correlation between coverage and health outcomes.[263] One example where this link has been proven is in the case of breast cancer. Because breast cancer is a disease that is to a large degree curable if caught in the early stages, it makes sense that women should be provided with adequate screening and early treatment options. However, the researchers of the Harvard study found that because hospitals that care for large numbers of uninsured patients and medicaid patients often use less thorough screening processes, these patients have higher rates of morbidity and mortality from the disease.[264] Uninsured women and women covered by medicaid have significantly more advanced stages of the disease than privately insured women when initial diagnosis is made. Thus, the survival rate of these women is less than that for privately insured women. Women without private insurance may not only have less access to breast cancer screening (including access to a primary care physician who can recommend preventive procedures), but also may be less aware of their options such as self-examinations and mammograms.[265]

Services that are expressly covered by medicaid have been denied to patients by doctors who have offered high cost and low reimbursement rates as the reason for not administering the procedures. For example, one study found that nationwide, 44 percent of physicians providing obstetric services turn away medicaid patients because reimbursement is low and the paperwork is cumbersome.[266] A recent *New York Times* article reported that medicaid patients routinely have been forced to pay hundreds of dollars in cash to receive pain relief, such as epidurals, during childbirth, despite medicaid regulations stating that pregnant patients are not to be charged for prenatal care, delivery, or other medical procedures that relate to pregnancy.[267] One patient was denied an epidural during labor, even though it had been ordered in advance by her obstetrician, because she had not prepaid for it. Another patient was asked to pay $400 in cash just hours before delivery. When the anesthesiologist refused to accept a check or credit card payment, the patient was forced to contact relatives to have the money wired, but by the time the money arrived, she had already given birth.[268] These examples illustrate the ways in which the health care industry treats publicly insured or uninsured individuals as second-class patients.

There are volumes of similar instances where women have been either denied treatment altogether or have faced difficulty obtaining services because of their method of payment. One author explains how women with special needs are often denied treatment because they rely on public assistance:

> [M]any poor women get fragmented care, rarely seeing the same doctor twice. Women with special needs, drug treatment, for instance, may be unable to find a treatment facility that will accept Medicaid.
>
> For the poor who use [emergency rooms] for primary care, the picture may even be worse. A study done at a California ER found that seriously ill patients who sought care in the ER left after waiting more than six hours to be seen. The researchers found that those who left had the same need for medical care as those who stayed. Ironically, when asked by the researchers why they left, many said they felt "too ill" to stay. Others had to return to work, to care for children, or left because they had transportation problems, all familiar obstacles for the poor seeking medical care.[269]

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[262] Vera et al., "Breast Cancer and Poverty," pp.7–8.

[263] John Z. Ayanian, Betsy A. Kohler, Toshi Abe, and Arnold M. Epstein, "The Relationship Between Health Insurance Coverage and Clinical Outcomes Among Women With Breast Cancer," *New England Journal of Medicine*, vol. 329 (July 1993), pp. 326–31.

[264] Ibid.

[265] Ibid.

[266] Nechas and Foley, *Unequal Treatment*, p. 173.

[267] Robert Pear, "Mothers on Medicaid Overcharged for Pain Relief," *New York Times*, Mar. 8, 1999, p. A–1.

[268] Ibid.

[269] Nechas and Foley, *Unequal Treatment*, p. 174.

Welfare Reform and Health Care Financing

"Cutting off Medicaid and other funds may be politically expedient, but it will be a failure economically and a tragedy medically."[270]

The welfare reform effort of 1996, signed into law as the Personal Responsibility and Work Opportunity Reconciliation Act (PRWORA),[271] has changed the structure of public assistance and consequently affected health care both directly and indirectly. One of the direct effects of welfare reform has been a reduction in medicaid use by those who qualify, and ultimately an increase in the number of uninsured. A second, less direct but perhaps more critical, result has been the increase in poverty among those needing assistance. This in turn has caused a worsening of health status and an increase in the need for health care services.[272]

Under the Federal welfare reform legislation, the Aid to Families with Dependent Children (AFDC) program was changed to a new block grant program called Temporary Assistance for Needy Families (TANF).[273] States were given the ability to unlink medicaid eligibility from their new public assistance programs while maintaining the old AFDC program qualifications. That is, those who received medicaid before the new regulations were supposed to automatically retain medicaid eligibility. States were given the authority to modify or simplify medicaid eligibility standards as long as the 1996 medicaid rules are treated as minimum standards.[274]

Instead of tying medicaid eligibility to the new TANF rules, Congress required States to determine medicaid eligibility using the AFDC rules in place in each State. Under the new rules, medicaid would still be available to families with children under the age of 18 who have been deprived of the support of one or both parents, if the family's monthly income is less than the AFDC threshold established by the State.[275] These new guidelines were intended to maintain access to medicaid, and in some States, make the qualifications more inclusive. However, two additional provisions of the welfare reform laws have caused others to lose medicaid eligibility. The new law includes tightened eligibility criteria for coverage of disabled children who receive supplemental security income (SSI) (although some of these children may qualify for medicaid under other criteria).[276] Second, States will not receive Federal matching funds for coverage provided to legal immigrants within 5 years of their entering the country.[277]

Welfare reform has had a particular effect on the health status of ethnic minorities by limiting eligibility and access of noncitizens to public benefits.[278] Before the 1996 welfare reform, legal immigrants were generally eligible for medicaid and other Federal benefits.[279] Immigrants who entered the United States before the law's enactment may remain eligible for medicaid, but those who have arrived since are banned from receiving all Federal public benefits for at least 5 years, including medicaid.[280] These reforms, focused on stopping undocumented immigration and reducing benefits to immigrants, instead

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[270] Howard Minkoff, Tamar Bauer, and Theodore Joyce, "Welfare Reform and the Obstetrical Care of Immigrants and Their Newborns," *New England Journal of Medicine*, vol. 337 (Sept. 4, 1997), pp. 705–07 (hereafter cited as Minkoff, et al., "Welfare Reform and Obstetrical Care").

[271] Pub. L. No. 104–193, 110 Stat. 2105 (codified at 42 U.S.C §§ 1309–1397b and in scattered sections of 26, 42, and 47 U.S.C. (Supp. II 1996)).

[272] Welfare reform was promoted as a way to save money, yet only 1 percent of the Federal budget and 3 percent of States' budgets were devoted to welfare programs such as AFDC. Martha F. Davis, "Welfare Reform: A Women's Health Perspective," *Journal of the American Medical Women's Association*, vol. 51, no. 4 (August/October 1996), pp. 166–70 .

[273] *See* Pub. L. No. 104–193, title I, § 103(a), 110 Stat. 2110 (codified as amended at 42 U.S.C. §§ 601–619 (Supp. II 1996)). *See also* 63 Fed. Reg. 39,936 (1998); HHS, Administration for Children and Families, "Welfare: Temporary Assistance for Need Families (TANF)," fact sheet, Feb. 13, 1998, accessed at <http://www.acf.dhhs.gov/programs/opa/facts/tanf.htm> (hereafter cited as ACF, TANF Fact Sheet).

[274] Physician Payment Review Commission, *Annual Report to Congress* (Washington, DC: Physician Payment Review Commission, 1997), p. 416 (hereafter cited as PPRC, *Annual Report to Congress, 1997*). *See* ACF, TANF Fact Sheet.

[275] 42 U.S.C. § 1382c note §(2)(A) (Supp. II 1996). *See also* Pamela Farley Short and Vicki A. Freedman, "Single Women and the Dynamics of Medicaid," *Health Services Research*, part I, vol. 33 no. 5 (December 1998), pp. 1309–36.

[276] PPRC, *Annual Report to Congress, 1997*, p. 416.

[277] Davis, "Welfare Reform," pp. 166–70. Legal immigrants already on medicaid will not lose their eligibility as a result of the change in the law. Ibid.

[278] Hernandez and Charney, *From Generation to Generation*, p. 58.

[279] Minkoff, et al., "Welfare Reform and Obstetrical Care."

[280] Ibid.

deny treatment to infected individuals and facilitate the spread of diseases.[281] While the reform technically does make an exception for communicable disease, both documented and undocumented immigrants suffer from lack of treatment because they have no benefits and fear deportation should they seek treatment.[282] The action plan for HHS' Asian American and Pacific Islander Initiative on health acknowledges this effect of welfare reform, and states:

> For Asian Americans and Pacific Islanders living in the U.S., some health disparities may be exacerbated by recent changes in welfare laws that exclude new immigrants from a wide variety of federally financed benefits and services. The new restrictions could have a chilling effect on how Asian American and Pacific Islander communities around the country access health and human services.[283]

Before welfare reform, children in immigrant families were slightly more likely than children in U.S.-born families to receive public assistance.[284] Now, many children in immigrant families may be ineligible for important benefits, or have parents who are ineligible and who are therefore hesitant to secure benefits on behalf of their children.[285] It is particularly critical to monitor the impact of welfare reform on these children, because unlike any other group of children in the United States, those in immigrant families have to a large extent been barred from eligibility for medicaid and SSI.[286]

Women also face a disadvantage as a result of welfare reform. In 1993, of the 5 million families receiving AFDC, 90 percent were headed by women. Scholars have argued that attempts to convert medicaid to a block grant program with capped Federal funding levels and without automatic eligibility for prior AFDC recipients, will have significant negative implications for poor women's access to medical care and will further jeopardize the health of their families.[287]

Pregnant women and newborns are especially vulnerable to critical health risks associated with poverty. As benefits decrease, poor nutrition and other risks for illness increase. Maternal undernutrition may contribute to low birthweight and infant disability and mortality.[288] In addition, poor families' inability to afford basic necessities, including nutritious food, has an immediate effect on children's development.[289]

Although the welfare reform law makes only minor explicit changes in the medicaid programs, some analysts believe there may be greater indirect effects, ultimately reducing the numbers of people receiving medicaid benefits.[290] Due to the disproportionately large numbers of women and minorities who rely on medicaid for health care coverage, these changes will have a disparate effect on their ability to obtain medical services. For example:

> If the enrollment of eligible individuals does drop, one result may be that some of the poor may delay seeking Medicaid coverage until confronted with an acute episode, especially a costly inpatient stay. This situation is especially problematic if it means these individuals also defer preventive care because they lack coverage. . . . The enactment of welfare reform heightens the urgency of [HHS] monitoring access to health care and reemphasizes the need to determine whether there is an increase of eligible, but not enrolled beneficiaries.[291]

In fact, HHS has made an effort to address the implementation and effect of the new welfare provisions. In response to the PRWORA legislation, the Department's Office for Civil Rights produced two draft guidelines for States and caseworkers outlining their responsibilities for ensuring that legal obligations under Federal civil rights laws are being met in the administra-

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281 Kimberly A. Johns and Christos Varkoutas, "The Tuberculosis Crisis: The Deadly Consequence of Immigration Policies and Welfare Reform," *Journal of Contemporary Health Law and Policy*, vol. 15 (fall 1998), pp. 101–30.

282 Ibid., p. 120. The reform law also requires the reporting of known undocumented immigrants who seek medical assistance. Ibid.

283 Bau, "We're Not All a Picture of Health," quoting from HHS, "Asian American and Pacific Islander Action Agenda," accessed at <http://www.omhrc.gov/aamain.htm>. For more information on the initiative, *see* chap. 7.

284 Hernandez and Charney, *From Generation to Generation*, p. 9.

285 Ibid., p. 58.

286 Ibid., p. 10.

287 Davis, "Welfare Reform," p. 166.

288 Ibid., p. 169.

289 Ibid.

290 PPRC, *Annual Report to Congress, 1997*, p. 416.

291 Ibid., p. 417.

tion of public assistance and welfare services.[292] The first guideline, "Civil Rights Laws and Welfare Reform—An Overview," explains the pertinence of Federal nondiscrimination laws to all federally assisted programs.[293] Examples are given for instances where potential violations may occur; however, none of these scenarios presents situations in which access to health care is hindered or denied for a specific group as a result of discriminatory implementation of the new welfare laws.[294] The documents also fail to acknowledge how PRWORA itself can potentially violate the civil rights of those who are disproportionately disadvantaged by its provisions. While these documents serve as an important overview of the implications of civil rights laws for welfare assistance in general, they fall short by failing to identify how PRWORA provisions will specifically and disparately affect health care for minorities and women. It is HHS' responsibility to monitor State agencies to ensure that those requiring public assistance to meet their health care needs are not subject to different treatment under the welfare reform laws.

The goal of programs such as TANF is to promote work and end long-term welfare dependency. A 5-year lifetime limit on assistance is one of the TANF's central provisions. In addition, there is a 2-year limit on the time anyone can receive assistance without working.[295] Thus, unless there are major State reforms or changes in Federal legislation, it is likely that more adults, particularly mothers, will lose medicaid coverage in the future. Programs under welfare reform may lead recipients to jobs, but many of those jobs will be low wage and will not offer health insurance coverage, resulting in an increase in the uninsured.[296] Therefore, by taking away medicaid at the AFDC threshold, an income level where relatively few workers can obtain private insurance, the current eligibility rules penalize low-income mothers for working.[297] Economists have theorized that the prospect of losing medicaid discourages single mothers from working, and "allowing two-thirds of Medicaid recipients to become uninsured is hardly a satisfactory way of rewarding women who move from welfare to work."[298]

The exact effect of welfare reform on medicaid is ambiguous at best. The liberalization of medicaid eligibility in some States may result in increased enrollment; and welfare reform, if successful in achieving its goal of moving recipients off public assistance to work, could in theory reduce the need for medicaid coverage as recipients obtain jobs with health insurance benefits. However, because work programs are in the early stages of implementation and welfare-to-work data have not yet been widely collected, it is as yet unclear whether this is occurring. On the other hand, welfare reform may have already had an adverse effect by reducing medicaid enrollees because many individuals leaving welfare are unaware of continuing medicaid coverage.[299]

Rather than take on both medicaid reform and welfare reform, Congress decided to break the link between medicaid eligibility and welfare dependency.[300] The impact on medicaid, and subsequently on financial access to health care, becomes lost in the often negative rhetoric surrounding welfare and other forms of public assistance. Although the decision to separate medicaid from welfare was intended to protect poor families' medicaid coverage from possible cutbacks in welfare, the result has been lower rates of enrollment among those considered eligible,

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[292] HHS, Office for Civil Rights (OCR), draft documents, "Civil Rights Laws and Welfare Reform—An Overview," and "Technical Assistance for Caseworkers on Civil Rights Laws and Welfare Reform," submitted by Kathleen O'Brien, special assistant, OCR, HHS, Apr. 13, 1999 (hereafter cited as HHS, OCR, "Civil Rights and Laws and Welfare Reform," Draft Document). These guidelines were produced in conjunction with the U.S. Departments of Labor, Justice, Education, and Agriculture, and the Equal Employment Opportunity Commission.

[293] For a complete discussion on Federal civil rights laws and statutes, *see* USCCR, *The Health Care Challenge*, vol. II, chap. 3.

[294] HHS, OCR, "Civil Rights Laws and Welfare Reform," draft document.

[295] Short and Freedman, "Single Women and the Dynamics of Medicaid," pp. 1309–10. Through welfare reform States are given the option of reducing the time limits on receiving assistance. *See* ACF, TANF Fact Sheet.

[296] Marilyn R. Ellwood and Leighton Ku, "Welfare and Immigration Reforms: Untended Side Effects for Medicaid," *Health Affairs*, May/June 1998.

[297] Short and Freedman, "Single Women and the Dynamics of Medicaid," p. 1311.

[298] Ibid., p. 1331.

[299] Ellwood and Ku, "Welfare and Immigration Reforms."

[300] Short and Freedman, "Single Women and the Dynamics of Medicaid," p. 1310.

despite States' expansion of eligibility.[301] An estimated 3 million children are uninsured, and with the connection being cut between medicaid and welfare programs, that number is expected to grow.[302]

Health Research

"When a new therapy or intervention is well understood in one population and in the health care system in which that population receives care, but not understood in other populations and other health care environments, medical science has failed the society it is supposed to serve."[303]

Health care research is a growing field. Funding for research has increased since 1960 from less than $1 billion to more than $35 billion in 1995. Traditionally, funding has come from a variety of sources. Several Federal agencies fund and/or conduct health research. HHS provides 85 percent of funding for health research and development; most of the funding (80 percent) comes from the National Institutes of Health, an operating division of HHS.[304] Other agencies involved in funding health care research include the Departments of Defense, Education, Agriculture, Veterans Affairs, and Energy.[305] In addition to Federal agencies, many other organizations conduct research on health related issues. Nonprofit organizations such as the American Cancer Society provide funds for research on specified topics.[306] Other research projects are funded by private industry and State and local governments.[307]

Figure 3.5 depicts the changes in health care research and development funding by Federal, State, and local governments, private industry, and private nonprofit organizations since 1960.[308] The Federal Government was the largest source of health research funding until the late 1980s, when private corporations began to increase their expenditures for health care and drug research. In 1995 the Federal Government spent $13.4 billion on health care research; State and local governments spent $2.4 billion; industry spent $18.6 billion; and nonprofit organizations spent $1.3 billion.[309]

There are stark differences in the health status, mortality rates, and disease rates among Americans of different races and ethnic backgrounds, as well as between men and women. Although different groups are susceptible to different diseases, and respond differently to drugs and other treatments,[310] women and minorities have not been included in health research studies in adequate numbers.[311]

In response to years of exclusion of women and minorities from health research, Congress enacted the National Institutes of Health Revitalization Act of 1993.[312] This law requires researchers to include women and minorities as subjects in clinical research trials and NIH to conduct outreach efforts to recruit both groups.[313] The NIH guidelines implementing the law state:

> In the case of any clinical trial in which women or members of minority groups will be included as subjects, the Director of NIH shall ensure that the trial is designed and carried out in a manner sufficient to provide for valid analysis of whether the variables being studied in the trial affect women or members of minority groups, as the case may be, differently than other subjects in the trial.[314]

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301 Ellwood and Ku, "Welfare and Immigration Reforms."

302 Charlotte Huff, "What They Don't Know Hurts: When Parents Think Welfare Reform Means They Lose Medicaid, Kids' Health Suffers," *Hospitals and Health Networks*, vol. 72, no. 9 (May 5, 1998), p. 16.

303 Otis W. Brawley and Heriberto Tejeda, "Minority Inclusion in Clinical Trials Issues and Potential Strategies," *Journal of the National Cancer Institute Monographs*, no. 17 (1995), pp. 55–57.

304 NCHS, *Health, U.S., 1998*, p. 359.

305 Ibid.

306 American Cancer Society, *Research Program Report*, accessed at <http://www.cancer.org/researchprogram/index.html>.

307 NCHS, *Health, U.S., 1998*, p. 358.

308 Ibid.

309 Ibid.

310 Judith H. LaRosa, Belinda Seto, Carlos E. Caban, and Eugene G. Hayunga, "Including Women and Minorities in Clinical Research," *Applied Clinical Trials*, vol. 4, no. 5 (May 1995), p. 31 (hereafter cited as LaRosa et al., "Including Women and Minorities").

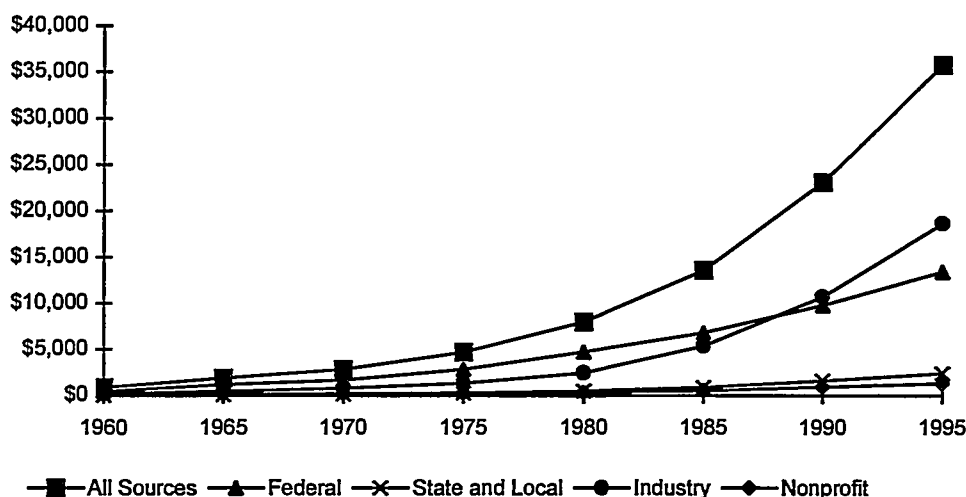
311 J. Claude Bennett, "Inclusion of Women in Clinical Trials—Policies for Population Subgroups," *New England Journal of Medicine*, vol. 329 (July 22, 1993), pp. 288–92.

312 Pub. L. No. 103–43, 107 Stat. 122 (codified in scattered sections of 8, and 42 U.S.C. (1994 & Sup. II. 1996))

313 LaRosa et al, "Including Women and Minorities," p. 33.

314 HHS, Public Health Service, National Institutes of Health, *NIH Guidelines on the Inclusion of Women and Minorities as Subjects in Clinical Research*, 59 Fed. Reg. 14508 (1994).

Figure 3.5
National Funding for Health Research and Development, 1960–1995



SOURCE: U.S. Department of Health and Human Services, National Center for Health Statistics, Health, *United States 1998 with Socioeconomic Status and Health Chartbook,* 1998, p. 358.

In 1995 the Centers for Disease Control (CDC) followed suit by establishing a policy to ensure that individuals of both genders and various racial and ethnic groups are included in all CDC-supported studies with human subjects. It has become CDC policy to identify significant gaps in knowledge about health problems that affect women and racial and ethnic minorities and to encourage studies that address these problems.[315] CDC policy states:

To the extent that participation in research offers direct benefits to the participants, underrepresentation of certain population subgroups denies them the opportunity to benefit. Moreover, for purposes of generalizing study results, investigators must include the widest possible range of population groups. . . . The guidelines are intended to ensure that individuals of both sexes, regardless of sexual orientation, and the various racial and ethnic groups will be included in CDC studies involving human subjects, whenever feasible and appropriate. Furthermore, it is the intent of CDC to proactively identify significant gaps in knowledge about health problems that affect women and racial and ethnic minority populations and to encourage research which addresses these problems.[316]

Inclusion of subgroups in clinical trials requires a change in study methodology. Opponents of these policy changes to research have argued that they are not cost effective, and that they increase the difficulty of completing health studies. However, a relatively simple strategy is to include persons from subgroups in the initial stages of project development. One commentator states:

Exclusion of a given subgroup from a study precludes formal inferences about the expected results for that subgroup. Therefore, a strategy that is commonly recommended is to design studies in which the subgroup composition of the study cohort mirrors that of the general population that would eventually receive the treatment.[317]

[315] 60 Fed. Reg. 47,947 (1995).

[316] HHS, Centers for Disease Control and Prevention, "Inclusion of Women and Racial and Ethnic Minorities in Research" Manual Guide, General Administration CDC–80, accessed at <http://www.cdc.gov/od/foia/policies/inclusio.htm>.

[317] Bennett, "Policies for Population Subgroups," pp. 288–92.

Race and Ethnicity

Minorities have either been exploited as research subjects for potentially harmful experiments, or ignored altogether despite differences in disease rates and/or manifestations of illnesses. Both of these misrepresentations are harmful to the well-being of racial/ethnic minorities and have contributed to a history of medical misinformation and ignorance about entire groups of people.

Exploitation as Subjects

The mere mention of research exploitation conjures up memories of the infamous Tuskegee study of untreated syphilis in black men. In that study, researchers followed the natural course of the disease in nearly 400 black men for decades, withholding treatment from 1932 to 1972.[318] The manner in which these experiments were "scientifically" justified demonstrates the long-standing insensitivity and ignorance about race in health care. According to one scholar, the health professionals involved in the Tuskegee study based their research on harmful assumptions. They erroneously assumed that the disease affected blacks differently from whites and thus was a legitimate focus of research. This served as the justification for a black-only study.[319] They also justified their actions with the notion that since the subjects had no access to medical care, whatever was provided was better than what they would have received without the project. This way the use of these subjects posed no ethical dilemma, at least from the perspective of the researchers, since they were not withholding something the subjects would have received in the absence of the experiment.[320]

Research exploitation of minorities is not just an issue of the past. For example, in 1998 *The New York Times* reported that testing of fenfluramine, a now banned drug, was being conducted on black and Hispanic boys between the ages of 6 and 10 years old at the New York State Psychiatric Institute.[321] The drug was being used to test a theory that violent or criminal behavior may be predicted by levels of certain brain chemicals. This test was problematic for several reasons, the most obvious being that it was done on children unable to make the decision of whether or not to participate. Advocacy groups argued that these children were used in experiments for which there was no hope of medical benefit, and that in the process they may have been exposed to risks.[322]

The danger of such experimentation can be observed on another level. The theory tested by this research is inherently racist, suggesting that blacks and Hispanics are prone to violence and criminal activity. One patient advocate said, "These racist and morally offensive studies put minority children at risk of harm in order to prove they are generally predisposed to be violent in the future."[323]

As a result of such studies, many minorities are reluctant to participate in health research. According to the HHS Office of Minority Health newsletter, *Closing the Gap*, a forthcoming article examines African Americans' attitudes toward research. The study found that African Americans believe that signing a consent form is essentially the same as waiving their rights. The study also revealed that, as a result of the Tuskegee study, many African Americans fear being treated like "guinea pigs." The study concludes that researchers need to acknowledge such concerns and ensure that the purpose of research is clearly explained to potential participants.[324]

Absence from Research

The absence of minorities in research stems partly from the unwillingness of many to participate. A *Newsday* article citing several examples of exploitation of minorities in health research suggests that today minorities are hesitant to participate in research studies, and receive treatment, because of the distrust created by earlier exploitation and discrimination.[325]

Minority groups often view medical research with suspicion. Many minorities, African Americans in particular, have personally experienced

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[318] Smith, *Health Care Divided*, p. 25.

[319] Ibid.

[320] Ibid.

[321] Philip J. Hilts, "Experiments on Children are Reviewed," *New York Times*, Apr. 15, 1998, p. 3–B.

[322] Ibid.

[323] Ibid.

[324] Michelle Meadows, "Study Explores African Americans' Attitudes Toward Research," *Closing the Gap*, May/June 1999, p. 7, citing Gisell Corbie-Smith, et al., forthcoming article in *Journal of General Internal Medicine.*

[325] Curtis L. Taylor, "Mistakes In the Past, Fears in the Present," *Newsday*, Dec. 4, 1998, p. A–08.

abuses while in hospitals and clinics.[326] In addition, Hispanics and African Americans frequently believe that medicine offers little hope, so they often do not seek medical attention and will not volunteer to participate in studies. Further, there is some degree of skepticism as to the motives of medical researchers based on the mandated inclusion of minorities in research trials.[327] Potential subjects may wonder if the researcher is simply filling a quota as opposed to having the patient's best interests in mind.

The widespread distrust of the medical industry necessitates the recruitment of more minorities into careers in biomedical research. Perhaps this will alleviate some of the concerns of minority patients and at the same time draw attention to minority health issues. According to an article in *Black Issues in Higher Education*, currently only 0.37 percent of biomedical research funds are awarded to black scientists.[328] This problem is attributed to the lack of minorities in scientific and research careers.[329]

Distrust of the medical community and other barriers, including language, lack of transportation, inconvenient clinic hours, and potential for lost wages, not only make participating in trials a low priority but make it an impossibility for many minorities.[330] Since economic barriers often make even necessary health care an impossibility, the resulting poorer health status among minority populations makes recruiting healthy research participants difficult.

On the other hand, there is evidence that researchers have excluded minorities, whether intentional or not, from trials. Broad-based inclusion of minorities in clinical trials is a civil rights issue as well as a sociopolitical one.[331] Despite the volumes of literature suggesting the importance of race, ethnicity, and culture in health, the seeking of health care, and treatment, there is relatively little information available on the racial, ethnic, and genetic differences that affect the manifestations of certain illnesses and their treatments. For example, certain antihypertensive drugs, such as beta blockers, are less effective in African American men than white men.[332] Furthermore, drug effectiveness and interaction can be different among individuals within racial or ethnic groups, which further justifies the need for a diverse research population. Population diversity increases scientific validity and the ability to generalize research results.[333] According to one researcher, different ethnic and racial groups "comprise important subpopulations whose special needs and responses to medical treatment have traditionally been undervalued or ignored."[334]

Researchers must make the effort to include minority subjects through community-based outreach and education. If the outreach is done effectively, inclusivity in trials will be attainable. One study by the National Cancer Institute's Minority-Based Community Oncology Program showed that despite all the previously mentioned determinants, minority patients will enter clinical treatment trials in proportions to majority patients when treated in the appropriate environment.[335] Often, health care providers do not offer the option of entering trials to minorities based on the assumption that these patients are unwilling to participate. The existence of trials must be made known, available, and convenient to all individuals. Further, representation, to be proportionally accurate, must mirror incidence rates and not general population percentages. That is, the percentage of African Americans in clinical cancer trials should coincide with their cancer rates.[336]

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326 Brawley and Tejeda, "Minority Inclusion in Clinical Trials," p. 56.

327 Ibid.

328 Leigh Fortson, "Biomedical Research Warfare," *Black Issues in Higher Education*, Mar. 18, 1999, p. 25.

329 Ibid., pp. 26–28. *See* chap. 2 and USCCR, *The Health Care Challenge*, vol. II, chap. 3, for discussions of medical school admissions.

330 Brawley and Tejeda, "Minority Inclusion in Clinical Trials," p. 56.

331 Ibid., p. 55.

332 Ibid.

333 Ibid.

334 Richard A. Levy, "Ethnic and Racial Differences in Response to Medicines: Preserving Individualized Therapy in Managed Pharmaceutical Programmes," *Pharmaceutical Medicine*, vol. 7 (1993), pp. 139, 141 (hereafter cited as Levy, "Differences in Response to Medicines").

335 Brawley and Tejeda, "Minority Inclusion in Clinical Trials," pp. 55–57.

336 Heriberto A. Tejeda, Sylvan B. Green, Edward L. Trimble, Leslie Ford, Joseph L. High, Richard S. Ungerleider, Michael A. Friedman, and Otis W. Brawley, "Representation of African Americans, Hispanics and Whites in National Cancer Institute Cancer Treatment Trials," *Journal of the National Cancer Institute*, vol. 88 (1996), pp. 812–16.

The limited health research that has been done comparing ethnic and racial groups has revealed that there are "significant differences among racial and ethnic groups in metabolism, clinical effectiveness and side effects of important medicines."[337] Thus, as one author has stated:

Ethnic and racial minorities are subject to greater risks if they are prescribed a so-called "equivalent" medicine because substantial evidence indicates that, in some cases, dosage adjustment may be necessary or that the drug has toxic side effects because they cannot tolerate the standard dosage levels. Institutional drug formularies and step-care protocols should be broad enough to allow rational choices of medicines and dosages for all patients, regardless of race or ethnic origin.

Pharmaceutical companies should continue to include significant numbers of ethnic and racial subgroups in metabolic studies and clinical trials in instances where genetic polymorphism for that class of medicine is relevant.[338]

Gender

Women have traditionally been excluded from clinical trials. As a result biological or gender differences, including both physiologically and culturally determined factors, have been ignored. A better understanding of women's health issues is necessary for the improvement of women's health care as well as the broadening of education related to preventive care for all women.

The CDC guidelines clearly address the importance of the inclusion of women in research and articulate the necessity of modifying research protocols to address specific health concerns of women:

A growing body of evidence indicates that the health conditions and needs of women are different from those of men. Some health conditions are unique to women and others are more prevalent in women. For some illnesses, there are marked distinctions, not only in onset and progression of disease, but also in the preventive, treatment and educational approaches necessary to combat them in women. Furthermore, initial entry into the health care system may be different for some subgroups of women, such as low-income and uninsured women. Lesbians may also enter the health care system differently because they may be less likely to access prevention services, like cancer screening, because they may not utilize family planning services.

The Public Health Service Task Force on Women's Health Issues published a report in 1987 stating that it is becoming more important to note the environmental, economic, social, and demographic characteristics that influence a woman's health status. The Task Force focused on the direct and indirect effects these factors could have on the status of a woman's health and noted that when a woman is "outside the normal range of societal expectations," that is, she is of racial, ethnic or cultural minority or if she is physically or mentally disabled, her health status is potentially at greater risk. These basic observations are not always recognized or reflected in study protocols and proposals.[339]

Despite the necessity of addressing women's specific health concerns, it is estimated that, until recently, only 13 percent of the total NIH budget was spent on women's health issues, including breast cancer, ovarian cancer, menopause, estrogen replacement therapy, and osteoporosis.[340] Commentators contend that although NIH might argue that another 80 percent of its budget is spent on studying diseases that affect both men and women, this is misleading because the so-called "gender neutral" conditions are experienced differently by women and men.[341] Further, if women are excluded from those studies, the data gathered do nothing to advance the knowledge of those diseases in women.[342]

Historically, several reasons have been cited for the exclusion of women from clinical trials. According to one author:

The exclusion of women from research trials appears to stem from several factors. These include a perception of the male body as an adequate model of the norm, and the female body as "unnecessarily" complicated by hormonal cycles; the fear that gender stratified studies would require such large cohorts of participants that expense would render many experiments uneconomic; and concern that fertile women may become pregnant while on the study, and expose

[337] Levy, "Differences in Responses to Medicines," p. 140.

[338] Ibid., pp. 160–61.

[339] 60 Fed. Reg. 47,947 (1995).

[340] Nechas and Foley, *Unequal Treatment*, pp. 22–23.

[341] Ibid., p. 23.

[342] Ibid.

their fetuses to potentially damaging substances that would manifest themselves in birth defects.[343]

Thus, fear of extra expenses and liability have been used as excuses for excluding women from health research.[344] Ironically, the same researchers who argue that women's "differences" make research more difficult also claim that women are "just like men anyway," so it is appropriate to draw conclusions from all-male studies.[345] One adverse effect of such exclusion is that women are often prescribed drugs that have not been tested on women, and thus it is unknown whether these drugs may be harmful or less effective.[346]

Recently, scientists at NIH acknowledged that some drugs seem to work very differently in women than in men, due to hormones, metabolism, weight, and many unknown factors.[347] An NIH official stated, "[B]y unlocking these kinds of scientific gender mysteries, we can apply them to developing medications that are safe and that work in all individuals. . . . For the first time, we are documenting that men and women respond differently to drugs and sometimes with serious consequences, including death."[348] This discovery reemphasizes the need to use women routinely as subjects in clinical trials, including those for medical conditions that affect both genders. For example, it was recently discovered that an experimental drug used to treat a rare form of stroke worked well in male patients but not at all in women.[349]

One of the most controversial debates over the inclusion of women in clinical trials has surrounded the issue of pregnancy and potential harm to the fetus. An article in the *Journal of the National Cancer Institute* gives one example of the urgency of including women at all stages in their reproductive cycle in clinical research trials. The author cites a case in which a patient was diagnosed with ovarian cancer in her 18th week of pregnancy. Her options were to either terminate the pregnancy, undergo chemotherapy, or do nothing. There was a lack of knowledge on the effects of powerful cancer-fighting drugs in pregnant women.[350]

The reality is that 70 to 80 percent of pregnant women need some form of prescription medicine.[351] Knowledge of this fact seems to have caused some medical researchers to now include women at all stages of life in clinical trials. In 1993, the *New England Journal of Medicine* cited another example of the benefit of drug therapy trials on women. Researchers in the AIDS Clinical Trial Group reported that AZT use by pregnant women brought "startling results" in preventing maternal-fetal transmission of the AIDS virus. The AZT study uncovered a valuable finding, which would have remained hidden had pregnant women not been used in the clinical trials.[352]

The negative effects of the absence of women in clinical trials are not limited to drug therapy. Women also need to be included in studies of disease diagnosis and treatment options. In 1991 the Council on Ethical and Judicial Affairs of the American Medical Association observed that "the very factors that lead to the exclusion or underrepresentation of women are evidence of the importance of including them."[353] This is especially true in instances where women and men respond differently to treatment methods.

Perhaps the most egregious example of the exclusion of women from the clinical study of a health condition that almost exclusively affects women was a project that examined the effect of obesity on breast and uterine cancer. All of the study participants were men.[354] The study examined the effects of particular nutrients on es-

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343 R. Alta Charo, "Protecting Us to Death: Women, Pregnancy, and Clinical Research Trials," *St. Louis Law Journal*, vol. 35 (fall 1993), pp. 140–41.

344 Ibid., pp. 143–45.

345 Nechas and Foley, *Unequal Treatment*, p. 26.

346 Charo, "Protecting Us to Death," p. 145.

347 "Researchers: Drugs Affect Men and Women Differently," *Daily Progress* (Charlottesville, VA), June 6, 1999, p. A–3.

348 Ibid.

349 Ibid.

350 Susan Jenks, "Role for Pregnant Women in Clinical Trials Debated," *Journal of the National Cancer Institute*, vol. 86 (December 1994), pp. 1820–22.

351 Ibid.

352 R.B. Merkatz, R. Temple, S. Subel. K. Feiden and D.A. Kessler, "Women in Clinical Trials of New Drugs: A Change in Food and Drug Administration Policy," *New England Journal of Medicine*, vol. 329, no. 4 (July 22, 1993), p. 271.

353 AMA, "Gender Disparities," pp. 559–62.

354 Rothenberg, "Gender Matters," citing Laurence and Weinhouse, *Outrageous Practices*. *See also*. Rebecca Dresser, "Wanted: Single, White Male for Medical Research," *Hastings Center Report*, January/February 1992, pp. 24–29.

trogen metabolism, and researchers chose only male subjects in the belief that estrogen metabolism is similar in men and women.[355]

There has also been a lack of women subjects in experimental AIDS therapies, despite the fact that they make up the fastest growing population of AIDS patients.[356] In a study, women suffered toxic side effects when given AZT treatments at dosages measured on the 70 kilogram (154 pound) male model. In 1992, when studies were being conducted on the effectiveness of AZT compared with the drug deoxyinosine, only 4 percent of the participants were women, too small a sample to draw accurate conclusions.[357] This exclusion from research also may explain why women are less likely that men to receive treatment drugs, such as AZT, even after taking into account such factors as race, insurance status, and mode of transmission.[358]

Several well-known studies of cardiovascular disease have also only used male subjects for observation. Yet heart disease is the single largest killer of women, and women in their sixties die of heart disease in equal numbers to men.[359] In fact, cardiovascular diseases kill twice as many women as all types of cancers combined.[360]

> Based on the findings of studies of heart disease and cholesterol that included men only, the American Heart Association recommended a diet that could actually elevate the risk of heart disease for women. A study of 51,529 male health professionals begun in 1986 suggested that moderate drinking and a decrease in heart disease are causally related. It is unclear, however, whether the result of this study can be extrapolated for application to women's health. For example, unlike men, "women who consume moderate quantities of alcohol have an increased risk of breast cancer." . . . In 1998 the results of a government funded study of 20,000 male physicians revealed that small doses of aspirin would help prevent heart attacks. . . . There was no data to substantiate whether an aspirin a day for women would have any impact on their risk of heart disease.[361]

The misinformation resulting from gender-biased research has potentially life-threatening ramifications. The lack of research contributes to a lack of knowledge about prevention and treatment procedures, leaving health care providers to rely on speculation and assumptions:

> Exclusion of women from studies because of an assumption that cardiovascular disease is comparable in women and men, "has resulted in sizable gaps in our knowledge about gender differences in efficacy of preventive strategies, . . . diagnostic methods, responses to medical and surgical therapies, and clinical outcomes for coronary heart disease." One physician has said, "If a fifty-year-old man goes to the doctor complaining of chest pains, the next day he will be on a treadmill taking a stress test. If a fifty-year-old woman goes to the doctor and complains of chest pains, she will be told to go home and rest."[362]

One commentator tells of a case where a 59-year-old woman went to her physician and complained of chest pains, which she had lived with for 5 years. The patient felt that her doctor was annoyed with her for coming in. He diagnosed the problem as a hiatal hernia, and prescribed that she take an over-the-counter antacid every 20 minutes. When the pain became unbearable, the patient went to an emergency room where a cardiologist discovered that three of her vessels were 75 percent clogged and one was completely clogged. She was rushed into quadruple bypass surgery, without which the cardiologist believed she would have died.[363]

Simply adding women to clinical trials does not eliminate the problem of inadequate representation in research. Women must be targeted as subjects, with differences and similarities factored in, for research to be effective and inclusive. Differences among women such as race, ethnicity, age, child-bearing status, and socioeconomic status may affect overall health status as well and must be considered. Including white women in an experimental group may yield

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355 Rothenberg, "Gender Matters," p. 1208.

356 Ibid., p. 1209.

357 Ibid.

358 Laurence and Weinhouse, *Outrageous Practices*, p. 150. The authors cite data from the Robert Wood Johnson Foundation's AIDS Health Service Program that indicate 65 percent of the men studied, but only 30 percent of the women, were offered AZT as a treatment.

359 Patricia Aburdene and John Naisbitt, *Megatrends for Women* (New York: Villard Books, 1992), p. 134.

360 Ibid., p. 137.

361 Rothenberg, "Gender Matters, " pp. 1209–10.

362 Ibid., p. 1210, citing Nanette K. Wenger, "Exclusion of the Elderly and Women from Coronary Trials: Is Their Quality of Care Compromised?" *Journal of the American Medical Association*, vol. 268 (1992), pp. 1460–61.

363 Aburdene and Naisbitt, *Megatrends*, pp. 137–38.

knowledge relevant to treating white women, but not for treating women of color.

One example of the need to make research more inclusive is the difference in rates of breast cancer among women. Guidelines that recommend screening for women 40 years of age and older ignore the higher than average risk for breast cancer among black women younger than 40.[364] Adequate research is necessary to determine whether separate guidelines should be established for black women, as well as other racial and ethnic groups of women.

Asian American women are notably missing from clinical research. There are several reasons for this absence, including lack of physician referrals, language difficulties, immigration issues, and cultural differences. A team of researchers in California interviewed members of various Asian American communities and found that resistance to participation for many Asian American women was because most clinical studies focus on the individual, whereas many Asian Americans may prefer not to draw attention to themselves or their own health, but rather take a more global community approach to health. The participants' responses also suggested that Asian Americans tend to be more modest about sharing their medical histories with health professionals.[365]

In a recent issue of *Women's Health Watch*, a publication of the Asian and Pacific Islander American Health Forum, several Asian American women were asked what types of research they believe are needed to target Asian American/Pacific Islander women. Although their responses varied, a common theme was the need for research focusing on health concerns specific to Asian American women, and to inform these women of available services. One respondent stated:

> I know that I am an educated young woman in America and I still know very little about my own health and other issues related to women's health. Especially, I think when we read the health statistics the young women and even the older women do not take advantage of the services that are provided. We need just the basic data on the primary common diseases in Asian American communities and what kinds of health services are available to women. [We need to have] this information available, and not just talk about them but actually hand them to community members and to women.[366]

Another Asian American woman said:

> I think it would be interesting to do girls' and adolescent health. . . . I haven't read a lot of information on mental health problems and issues that young people have, especially within the immigrant and refugee communities. I find that the girls that I work with, [and] their families have much stress and some have post traumatic stress syndrome. We want to know how the children handle that. I think research on mental health or even just adolescent health is greatly needed.[367]

In a 1998 summit meeting of the National Asian Women's Health Organization, Surgeon General David Satcher stated that to increase participation of Asian American women in clinical trials, it is necessary to establish better community trust. He said that this would not only encourage inclusion of those willing to participate, but would also enable outreach to those least likely to participate, including uninsured women. He said, "Our goal must be universal access to health care, and inclusivity for all ethnic groups in clinical trials can be an important element in reaching that goal."[368]

African American women also often are absent from clinical trials. They may refuse to participate because of a lack of trust in the health care system. In an attempt to better understand why so many minority women refuse to participate in clinical trials, researchers interviewed women who had refused participation in the Women's Health Initiative, a national study on the efficacy of low fat diets, hormone replacement therapy, and vitamin D/calcium supplementation to prevent coronary heart disease,

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[364] HHS, National Institutes of Health, Office of Research on Women's Health, *Women of Color Health Data Book* (1998), p. 94.

[365] Mike Miller, "Asian-American Women: How Should They Be Represented in Clinical Trials?" *Journal of the National Cancer Institute*, vol. 90 (Nov. 18, 1998), pp. 1698–99 (hereafter cited as Miller, "Asian-American Women in Clinical Trials").

[366] "What Types of Research Do You Think Are Needed For Asian American and Pacific Islander Women?" *Women's Health Watch*, Asian and Pacific Islander American Health Forum, winter 1998, pp. 2–3.

[367] Ibid.

[368] Miller, "Asian-American Women in Clinical Trials," pp. 1698–99.

breast cancer, colorectal cancer, and osteoporosis in post-menopausal women.[369] The researchers found that black women are more likely than white women to believe that clinical research is unethical, that researchers do not care about them, and that by participating in research they would not have access to better care.[370] African American women surveyed also stated that they would be more likely to participate if the researchers were also black.[371]

Changes in research guidelines adopted by the Nation's major research agencies show a growing recognition of the need for inclusion of women in research. However, inclusion has not been global enough, nor has it been swift enough, to match the urgency of adequate medical knowledge about all individuals. Expanding medical knowledge is a critical, yet rapidly changing endeavor that should encompass diverse aspects of health care, including financing, policy, delivery, and outcomes. Until all areas of research include women's health needs, solutions will not be understood. It has been stated:

> While the past two decades have seen important gains in research in women's health and women's health care, it must be emphasized that we are only at the beginning of our knowledge about health and disease in women, and continued funding is critical in order to address the questions, further understand the findings, and confirm the recommendations that are emerging from these initial studies. Research is needed in biomedicine, in health behavior, in screening technology, in the effectiveness of alternative modes of health care financing and delivery of disease prevention, and in the policy implications of areas of concern surrounding women's health.[372]

[369] Charles P. Mouton, Sonja Harris, Susan Rovi, Patty Solorzano, and Mark Johnson, "Barriers to Black Women's Participation in Cancer Clinical Trials," *Journal of the National Medical Association*, vol. 89, no. 11 (1997), pp. 721–27.

[370] Ibid., p. 726.

[371] Ibid.

[372] The Commonwealth Fund, *Prevention and Women's Health: A Shared Responsibility*, Policy Report of the Commonwealth Fund Commission on Women's Health (New York: The Commonwealth Fund, September 1996), p.31.

Chapter 4

Health Care Programs and Initiatives at the Federal, State, and Local Levels

Many initiatives have been implemented that are aimed at reducing the health disparities that exist based on race, ethnicity, and gender and that target the specific health concerns of women and minorities. Although the initiatives vary in scope and mission, they share a common set of goals including: producing health practitioners who are skilled in providing quality health care for women and minorities, developing researchers who understand the necessity of tackling the important health concerns of women and minorities, and improving access to gender and race/ethnicity-specific, culturally competent health services within a changing health system.

When viewed in a civil rights context, these health care programs and initiatives have the potential to work toward eliminating disparities while improving the health status of traditionally underserved groups. But initiatives alone, in particular reactive uncoordinated initiatives, cannot narrow the gap in health care nor eliminate health care disparities. The Office for Civil Rights (OCR) in the U.S. Department of Health and Human Services (HHS) is the Federal office designated to enforce civil rights statutes relating to health care. However, several HHS entities and most State and local health care organizations have little or no contact with OCR, and as a result, civil rights concerns are not integrated into their initiatives.

Civil rights concerns need to be included in all health care programs and initiatives, and the goals of the initiatives must transcend the programmatic level and become institutionalized in all aspects of health care delivery and research. Emphasis should be placed on the promotion of health and the *prevention* of inequality in health care, instead of merely targeting current problems. That is, measures taken to improve health status must be proactive, not reactive. This can be achieved through greater collaboration at all levels—Federal, State, and local—and through assistance from Federal and non-Federal civil rights experts. All entities involved in eliminating disparities in health care must recognize programs that work and replicate those programs on a universal level.

HHS Initiatives on Health Care for Women and Minorities

HHS has several health care programs and initiatives concerning minority and women's health disparities. Four of the initiatives have been decreed by Executive orders. Three of them concern support for educational institutions—the Historically Black Colleges and Universities Initiative, the Hispanic Agenda for Action, and the Tribal Colleges and Universities Initiative. Other initiatives include the President's Race and Ethnic Health Disparities Initiative and the Asian American and Pacific Islander Initiative which was established by Executive order in June 1999.[1]

HHS' Deputy Secretary requires high-level staff, including OCR's deputy director, to regularly report on the progress of a variety of initiatives relating to equal access.[2] In addition, HHS' Deputy Assistant Secretary for Minority Health has called on all of the operating divisions to make efforts to reduce racial/ethnic disparities in health care access.[3] HHS allocates funds each

[1] Exec. Order No. 13,125; 64 Fed. Reg. 31105–07.

[2] Kathleen O'Brien, special assistant to the director and Patricia Mackey, deputy to the associate deputy director, Office of Program Operations, Office for Civil Rights (OCR), U.S. Department of Health and Human Services (HHS), interview in Washington, DC, Oct. 16, 1998, p. 9 (statement of Mackey) (hereafter cited as O'Brien and Mackey interview).

[3] Ibid., p. 8 (statement of Mackey). *See* U.S. Commission on Civil Rights (USCCR), *The Health Care Challenge: Acknowledging Disparity, Confronting Discrimination, and Ensuring Equality*, *vol. II, The Role of Federal Civil Rights Enforcement Efforts*, September 1999 (hereafter cited as USCCR, *The Health Care Challenge*, vol. II), chap. 5 for a discussion

year to ensure that the operating divisions are able to implement minority and women's health programs. However, in comparison to the Department's total funds, the monies slated for minority and women's issues are minuscule.[4] For fiscal years 1998 and 1999, approximately 1 percent of HHS' total funds were used for minority health initiatives and programs; the amount has been increased for FY 2000 to approximately 2.5 percent.[5] Women's programs and initiatives fare slightly better at approximately 13.5 percent of all HHS funds in fiscal years 1998 and 1999, and a projected 14.2 percent for FY 2000.[6]

According to the Surgeon General, it is very difficult for offices of minority health and women's health to obtain funding or influence the agenda of their respective agencies.[7] The final determination for the budget allocation for an office often rests with Congress. For example, when the budget request was made for the HHS Initiative to Eliminate Racial and Ethnic Disparities in Health, only one-third of the amount requested was granted. According to the Surgeon General, "Congress is 90 percent white men and they have the tendency to understand best those problems that relate to them. They often make decisions based on their own experiences and interests."[8] However, the Surgeon General stated that it may be easier for the National Institutes of Health (NIH) than other agencies, to get requested funding for its minority and women's initiatives because Congress can better identify with those diseases that affect their community as well.[9] Lawmakers, Nobel laureates, disease victim advocates, drug companies, celebrities, and journalists have joined forces to push for doubling the NIH budget over the next 5 years.[10] Many of these individuals, or someone they know, have been affected by illnesses such as cancer, neurological conditions, paralysis, and Alzheimer's disease. For lawmakers, increased funding for NIH is a concrete means to improve the lives of all of their constituents.[11] In the past, Congress has mandated NIH to pay more attention to women's health issues, alternative medicine, and other areas.[12]

However, the support for increased funding at NIH also has generated criticism. Some experts think that budget appropriators have not asked enough questions about how NIH can absorb this massive infusion of money.[13] Others contend that increased funding for NIH would come at the expense of other programs.

Office on Women's Health

The Office on Women's Health (OWH) within the Office of Public Health and Science (PHS) was established in 1991 as a result of pressure from women's advocates.[14] The OWH is not a program office, has no formal authorization or statutory language regarding its existence and, therefore, does not have the authority to give grants.[15] Its mission is "to improve the health of American women of all ages, races, and ethnicities by advancing and coordinating a comprehensive women's health agenda" throughout HHS.[16] The Office on Women's Health coordinates with consumer and health care professional groups, public and private organizations,

of the operating divisions' missions and civil rights related activities.

[4] *See* appendices for information on the budgets of the operating divisions. The figures provided to the Commission list funds for only seven of the operating divisions and the Office of Minority Health and the Office on Women's Health in the Office of Public Health and Science. It is unclear whether additional funds are being allocated to other departmental agencies or if research monies are included.

[5] Novella Matthews, Office of Budget, Office of the Assistant Secretary of Management and Budget, HHS, fax to Eileen Rudert, Office of Civil Rights Evaluation, USCCR, no date (re: request for information), attachment, "Minority Health and Assistance: Direct/Specialty Targeted Programs Only" (hereafter cited as HHS Office of Budget, Response to Information Request). *See* app. 4.1.

[6] HHS, Office of Budget, Response to Information Request, attachment, "HHS Women's Health." *See* app. 4.2.

[7] David Satcher, Surgeon General, HHS, interview in Washington, DC, Apr. 30, 1999, p. 2 (hereafter cited as Satcher interview).

[8] Ibid.

[9] Ibid.

[10] Sue Kirchhoff, "Progress or Bust: The Push to Double NIH's Budget," *Congressional Quarterly Weekly*, vol. 57, no. 19 (May 9, 1999), pp. 1058–62.

[11] Ibid., p. 1062.

[12] Ibid.

[13] Ibid., p. 1058.

[14] Wanda Jones, Deputy Assistant Secretary for Health (Women's Health), Office of Public Health and Science, HHS, interview in Washington, DC, Mar. 16, 1999, p. 2 (hereafter cited as Jones interview).

[15] Ibid.

[16] HHS, Public Health Service, Office of Women's Health, "Who We Are," accessed at <http://www.4woman.gov/owh/office/index.htm>.

and other government agencies to promote and conduct women's health research, health care services for women, and professional education and training. The office also sponsors a nationwide information phone line and provides information on women's health issues on its Web site.[17] In addition, there is a regional women's health coordinator in each of the 10 HHS/PHS regions.[18]

In recent years collaboration has increased between the OWH and the Office of Minority Health (OMH).[19] For example, the OMH has assisted the OWH with the National Centers of Excellence in Women's Health program.[20] The OWH funds 18 centers which absorbs about one-third of its budget.[21] Through these centers the OWH has been able to establish and evaluate a new model health care system that unites women's health research, medical training, clinical care, public health education, community outreach, and the promotion of women in academic medicine to improve the health status of diverse women across the lifespan.[22] The National Centers of Excellence in Women's Health program provides funds to health care facilities to serve their communities, particularly with regard to women's and minorities' health issues. Currently, all awardees have been academic medical centers, but work is being done to include community-based facilities as well. Because there are many similar issues of concern for women and minorities, OWH and OMH convene together at headquarters for programmatic updates and to discuss new initiatives.[23]

The OWH and the HHS' Office for Civil Rights (OCR) had not collaborated as of March 1999. Until recently, the director of OWH was unaware of the function of OCR, nor did she know who the director was.[24] She did acknowledge that interaction with OCR could provide opportunities for addressing health care issues of women and minorities and said that she was going to take the first step by contacting OCR to set up a meeting.[25]

In the past, the relationship between the OWH and the operating divisions was strained because OWH often took credit for many of the initiatives being done in the offices of women's health within the operating divisions.[26] OWH is now often consulted for feedback on new grants or programs and asked to sit in on grant review processes.[27] Through the PHS Coordinating Committee on Women's Health, which was established to advise the Assistant Secretary for Health and the Deputy Assistant Secretary for Health (Women's Health) on current and planned activities across the PHS to safeguard and improve women's health, the Office of Women's Health interacts with the operating divisions' senior staff representatives who are members of the Committee.[28] The Coordinating Committee serves as a forum for the PHS agencies and offices to:

- Share ongoing and proposed initiatives in women's health and identify opportunities for collaborative activities.
- Provide advice and consultation to PHS OWH on its initiatives.
- Identify programs that can be shared with PHS regions to foster local activity on similar priorities.
- Receive information about priority issues identified by women's health coordinators at the regional level to discern the need for national initiatives.
- Identify and evaluate women's health issues likely to become policy-critical issues.
- Receive and disseminate information about women's health issues internationally and

[17] HHS, Public Health Service, Office on Women's Health, "Who We Are," accessed at <http://www.4woman.gov/owh/office/index.htm> on Jan. 4, 1999. The OWH phone line number is 800–994–WOMAN.

[18] Jones interview, p. 2.

[19] Ibid., p. 3.

[20] Ibid.

[21] Wanda Jones, Deputy Assistant Secretary for Health (Women's Health), Office of Public Health and Science, HHS, letter to Frederick D. Isler, assistant staff director for Civil Rights Evaluation, USCCR, June 28, 1999 (re: comments on draft report), p. 1.

[22] HHS, Public Health Service, Office on Women's Health, "National Centers of Excellence in Women's Health Fact Sheet," p. 1.

[23] Jones interview, p. 3.

[24] Ibid.

[25] Ibid.

[26] Ibid.

[27] Ibid.

[28] Wanda Jones, Deputy Assistant Secretary for Health (Women's Health), Office of Public Health and Science, HHS, fax to Margaret Butler, Office of Civil Rights Evaluation, USCCR, July 2, 1999 (re: PHS OWH Coordinating Committee), p. 1.

participate in the development of U.S. positions on policies on women in international forums.[29]

Although the office does not have the authority to provide support to programs aimed at increasing women's representation in medical professions, staff have drawn attention to the issue. The OWH has worked with medical organizations, such as the Association of American Medical Colleges, to develop a curriculum on women's health for medical schools.[30] The office publishes a directory of residency and fellowship programs in women's health.[31] The OWH convened the leading health profession organizations to address the underrepresentation of women and focused on the subjects of mentoring and career advancement.[32] The OWH also hosted competitions for Centers of Leadership in Academic Medicine, which extends to women and minority groups.[33] Included among the four medical schools that have received funding from the OWH are Meharry University, which is a historically black school and Eastern Carolina University, which is comparatively rural.

The office also has collaborated with NIH, the Health Resources and Services Administration (HRSA), the American Medical Women's Association, and the Association of American Medical Colleges to develop a women's health curriculum for use in medical education so that prospective physicians recognize gender differences in the causes, treatment, and prevention of diseases.[34] The OWH supports the recruitment, retention, and promotion of women in health care and biomedical careers.[35] The OWH established the Healthy Women 2000 National Education Initiative to encourage health-conscious behaviors in women and inform policymakers, health care professionals, and the public on critical women's health care issues.[36]

The OWH has been involved in many initiatives and programs that target specific health concerns for women. The office has established a Federal Coordinating Committee on Breast Cancer, which includes senior staff from various Federal Government Departments, and developed an inventory of Federal breast cancer programs, available in print and on the Internet.[37] The OWH has promoted innovative health behavior initiatives for women, including convening critical conferences, such as Smoking and the Health of Girls and Adolescent Women and Women's Health and Nutrition, to examine these risk factors for disease and disability in women and develop a plan for action.[38]

Office of Minority Health

The Office of Minority Health (OMH) in the Office of Public Health and Science was established administratively in 1985, as a result of a report published by a Task Force on Black and Minority Health.[39] The office was not created statutorily until 1990.[40] OMH advises the Secretary of HHS and the Office of Public Health and Science on program activities affecting American Indians, Alaska Natives, African Americans, Asian Americans, Pacific Islanders, and Hispanics.[41] The OMH resource center provides information on minority health issues. In addition, OMH is responsible for coordinating minority

[29] Ibid.

[30] Jones interview, pp. 3–4.

[31] Ibid., p. 4.

[32] Ibid.

[33] Ibid.

[34] HHS, Public Health Service, Office on Women's Health, "U.S. Public Health Service's Office on Women's Health Overview: Charting the Future for Women's Health—Informing and Educating," p. 2, accessed at <http://www.4woman.gov/owh/ov4c.htm> (hereafter cited as HHS, OWH: Informing and Educating).

[35] HHS, Public Health Service, Office on Women's Health, "About the U.S. Public Health Service's Office on Women's Health," March 1999, p. 2.

[36] HHS, OWH: Informing and Educating, p. 1.

[37] HHS, Public Health Service, Office on Women's Health, "U.S. Public Health Service's Office on Women's Health Overview: Charting the Future for Women's Health—Coordinating and Collaborating," p. 1, accessed at <http://www.4woman.gov/owh/ov4a.htm>.

[38] HHS, Public Health Service, Office on Women's Health, "U.S. Public Health Service's Office on Women's Health Overview: Charting the Future for Women's Health—Fighting Disease in Women," p. 2, accessed at <http://www.4woman.gov/owh/ov4b.htm>.

[39] Nathan Stinson, Acting Deputy Assistant Secretary for Minority Health, Office of Public Health and Science, HHS, interview in Rockville, MD, Mar. 30, 1999, attachment, p. 2 (hereafter cited as Stinson interview); *see also* HHS, *Report of the Secretary's Task Force on Black and Minority Health*, vol. I: executive summary, August 1985.

[40] Pub. L. 101–527, § 2, 104 Stat. 2312 (1990) (codified as amended at 42 U.S.C § 300u–6 (1994 & Supp. II 1996)).

[41] HHS, Office of Minority Health, "About OMH," accessed at <http://www.omhrc.gov/aboutomh.htm>.

health policies and programs and has entered into cooperative agreements with several organizations to conduct minority health projects.[42]

The OMH and OWH work closely on many projects and issues.[43] They develop educational materials, disseminate materials to the public through the OMH's resource center and the HHS publications clearinghouse, and are represented in planning meetings for policy discussions, conferences, and working groups. The OMH and the OWH hosted the first joint minority health and women's health State coordinators meeting in July 1999.[44]

One of the goals of the OMH is to ensure that issues related to minority health are integrated into the day-to-day operations of the operating divisions.[45] The operating divisions control a large portion of HHS resources and manage multiple programs that directly target minority communities.[46] The OMH does not have any formal means of ensuring the operating divisions are using minorities in research projects. However, every 2 years OMH is required to submit a report to Congress on minority health; appended to that report are summaries of minority-specific activities in which the operating divisions are involved.[47]

Most operating divisions have established and funded their own minority health offices, which interact extensively with OMH.[48] The operating divisions' offices of minority health vary in staff and scope, but all are members of the departmental Minority Initiatives Coordinating Committee. Regardless of the size and/or structure of the minority health offices, OMH's role is to support the activities of the offices and work with them to ensure that their programs and policies benefit racial and ethnic minorities.[49]

OMH regional consultants work closely with OCR regional representatives to highlight issues of concern. A representative from OCR is a member of the Departmental Minority Initiatives Coordinating Committee, which OMH runs and staffs; this committee represents one of the closet relationships the OMH has with OCR. The OMH also interacts with OCR through the HHS Data Council's Working Group on Racial and Ethnic Data. The working group is cochaired by OMH, and an OCR representative serves as a member of the group. The OMH and OCR also collaborated on a 1992 conference, Partners in Human Service: Shaping Civil Rights Policy for Asian Americans and Pacific Islanders.[50] In addition, OMH is currently working with OCR to respond to a congressional inquiry on how Congress and the Department should respond to concerns raised by a *New England Journal of Medicine* article that showed blatant bias in health care recommendations based on race and gender.[51]

Unlike the OWH, the OMH has grant-making authority.[52] Through cooperative agreements, the OMH and other agencies provide funding to organizations, such as the Interamerican College of Physicians and Surgeons, the Association of American Indian Physicians, the Hispanic Association of Colleges and Universities, the National Council of La Raza, the National Medical Association, and the National Minority AIDS Council, to develop and implement programs aimed at mentoring students and developing their interest in the health professions.[53] OMH participates in several summer minority youth initiatives; women's health activities, such as the HHS Women and AIDS working group; and programs at the local level.[54]

Departmental Initiatives

Healthy People

Healthy People is a national initiative to identify opportunities for improving the health

[42] Ibid.

[43] Stinson interview, attachment, p. 4.

[44] Ibid., p. 4.

[45] Ibid., p. 3.

[46] Ibid.

[47] Ibid., p. 7.

[48] Ibid., p. 4.

[49] Ibid.

[50] Nathan Stinson, Acting Deputy Assistant Secretary for Minority Health, Office of Public Health and Science, HHS, letter to Frederick D. Isler, assistant staff director for Civil Rights Evaluation, U. S. Commission on Civil Rights, June 29, 1999 (re: comments on draft report), p. 6 (hereafter cited as Stinson letter).

[51] Kevin A. Schulman et al., "The Effect of Race and Sex on Physicians' Recommendations for Cardiac Catheterization," *New England Journal of Medicine*, Feb. 25, 1999, pp. 618–26.

[52] Stinson letter, p. 5.

[53] Ibid., attachment, p. 5.

[54] Ibid., attachment, pp. 5–6.

of all Americans.[55] Begun in 1979, the program identifies goals, with public input, and monitors the Nation's progress in achieving those goals. The 1979 goals were expected to be met by 1990.[56]

However, in 1991, HHS released new objectives for improving the Nation's overall health status by the year 2000.[57] The Healthy People 2000 report identified 22 priority areas, including: physical activity and fitness, nutrition, substance abuse, violent and abusive behavior, clinical preventive services, educational and community-based programs, and HIV infection and other diseases.[58]

A 1995 review of the Healthy People 2000 initiative showed that progress was being made on more than two-thirds of the objectives identified in the 1990 report. However, the 1995 report noted several groups "continue[d] to experience disproportionately worse health outcomes than other Americans," including Americans with disabilities, individuals from lower income families, and members of minority groups.[59] The mid-course review provided revisions to the original objectives, included 19 new objectives, and identified 123 target populations.[60]

HHS is currently developing health objectives for 2010 through public comments, focus groups, and public meetings.[61] Proposed goals for this new initiative are increasing quality and years of healthy life and eliminating health disparities.[62] Achieving the goals of Healthy People 2010 relies on educational and community-based organizations to promote healthful lifestyles and provide health-related information. According to HHS, "Attainment of the Healthy People 2010 objectives and improvement in health outcomes in the United States by the year 2010 will depend substantially on educational and community-based efforts. These objectives should stimulate and encourage collaborative action and create healthier communities."[63]

Healthy People 2000 was established to narrow the gap in health disparities, while Healthy People 2010 was designed to eliminate the gap. Healthy People 2000 was not effective because it did not include as one of its goals vigorous civil rights enforcement at the Federal, State, and local levels. Although Healthy People 2010 is an ambitious project, it also lacks vigorous civil rights enforcement as one of its goals, and thus its ability to eliminate health disparities is questionable.

The numerous minority health initiatives implemented by the operating divisions have been in place for more than 10 years and still have not adequately been integrated into the Healthy People initiatives. Early enforcement of civil rights laws, when minority initiatives were first implemented by the operating divisions, may have eliminated the need for the Healthy People 2010 initiative and made the various operating division initiatives more successful.

Racial/Ethnic Disparities in Health Initiative

In 1998 the deputy to OCR's associate deputy director reported to the U.S. Commission on Civil Rights that HHS/OCR was in the early stages of an initiative on quality of care disparities for racial/ethnic minorities in conjunction with the operating divisions and Office of the Assistant Secretary for Planning and Evaluation.[64] The special assistant to OCR's director stated that OCR's efforts to work with HHS operating divisions and staff divisions to reduce racial/ethnic disparities in access to health care are part of the departmental contributions to the President's Initiative on Race.[65] This initiative is mounted independently of the four departmental Minority Health Initiatives.[66] The President called on HHS, in a

[55] HHS, Office of Public Health and Science, *Healthy People 2010 Objectives: Draft for Public Comment*, Sept. 15, 1998, Introduction, p. 1 (hereafter cited as HHS, *Healthy People 2010*).

[56] Ibid.

[57] HHS, *Healthy People 2000: National Health Promotion and Disease Prevention Objectives*, 1991.

[58] HHS, "Healthy People 2000 Priority Areas and LEAD PHS Agencies," accessed at <http://odphp.osophs.dhhs.gov/pubs/hp2000/ldagencies.htm>.

[59] HHS, Public Health Service, *Healthy People 2000: Mid-course Review and 1995 Revisions*, 1995.

[60] Ibid.

[61] HHS, "Healthy People 2010 Fact Sheet," accessed at <http://webhealth.gov/healthypeople/2010fctsht.htm>.

[62] HHS, *Healthy People 2010*, Goals, pp. 3, 19.

[63] Ibid., Educational and Community-Based Programs, p. 4–4.

[64] O'Brien and Mackey interview p. 9 (statement of Mackey).

[65] Kathleen O'Brien, special assistant, and Ronald Copeland, associate deputy director, OCR, HHS, interview in Washington, DC, Nov. 13, 1998, p. 4.

[66] Kevin Thurm, Deputy Secretary, HHS, Dear Colleague letter (re: progress of HHS' Asian American and Pacific

radio address in February 1998, to lead the Nation in an effort to eliminate racial and ethnic disparities in six health-focus areas by the year 2010.[67] In response to the President, Secretary of HHS Donna Shalala convened a departmentwide Steering Committee cochaired by the Assistant Secretary for Health and Surgeon General and the Assistant Secretary for Planning and Evaluation.[68] The heads of all HHS agencies are members of the Steering Committee. The cochairs have convened six working groups within HHS to prepare reports that examine the underlying causes of health disparities, research and data gaps, and interventions that could reduce and eventually eliminate disparities.

According to the director of OCR's Policy and Special Projects Staff (PSPS), every component of the Department, including OCR, is working on addressing issues related to inequities in health care, such as medical redlining, steering of minority patients to particular hospitals, access to a regular care provider, length of time waiting for care, continuity of care, adverse effects of hospital closure and relocations on minority communities, national origin related issues (including treatment of patients with limited English proficiency), reliance on hospital outpatient departments and emergency rooms, unequal participation of minorities and women in medical research programs at university/teaching hospitals, unequal access to health care financing programs, and inadequate minority participation in hospital construction programs.[69] According to the Deputy Assistant Secretary for Minority Health, although components of HHS are addressing the above mentioned issues, there has not been any systematic effort by the Steering Committee or OCR to monitor or report on the Department's progress.[70]

HHS' efforts to address racial/ethnic inequities in access to health care providers, quality of care received, and health status are guided by a senior level steering committee, established by the Secretary and cochaired by ASPE and the Surgeon General.[71] HHS has identified six focus areas in which racial/ethnic minorities experience serious disparities in health access and outcomes: infant mortality, breast and cervical cancer screening and management, cardiovascular disease, prevention of complications of diabetes, access to state of the art therapy for HIV infection, and child and adult immunizations.[72] These six areas were selected because they reflect, from HHS' perspective, areas of disparity that affect multiple racial and ethnic minority groups at all life stages.[73] However, the Commission's evaluation of HHS/OCR clearly demonstrates that OCR actions to address issues related to inequities in health care have been meager, or nonexistent, with the exception of treatment for patients with limited English proficiency.[74]

HHS acknowledges that the strategies for reducing racial/ethnic disparities for some indicators are not fully developed.[75] Advances in medicine and increased access to care can explain only partially the complex and often controversial issues surrounding racial/ethnic disparities in health status.[76] Other variables that contribute to health outcomes, such as socioeconomic status, education, and environment, must also be considered when determining a comprehensive strategy to reduce disparities.[77] HHS will therefore identify the gaps in knowledge and develop a research agenda to address them. The

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Island Initiative), Nov. 10, 1998, p. 2, accessed at <http://www.omhrc.gov/thurmltr/htm> (hereafter cited as Thurm, AAPI Letter).

[67] Stinson letter, p. 6.

[68] Ibid.

[69] Marcella Haynes, director, Policy and Special Projects Staff, and Kathleen O'Brien, special assistant, OCR, HHS, interview in Washington, DC, Nov. 16, 1998, pp. 11–12 (hereafter cited as PSPS interview). *See also* PSPS interview, pp. 6, 14, 15, 34–37, 40 (statement of Haynes); Ronald Copeland, associate deputy director, Office for Program Operations; Marcella Haynes, director, Policy and Special Projects Staff; Pamela Malester, deputy director, Quality Assurance and Internal Control Division; OCR, HHS, interview in Washington, DC, July 29, 1998, p. 3 (statement of Copeland) (hereafter cited as OCR interview, July 29, 1998); O'Brien and Mackey interview, pp. 8–9 (statement of Mackey).

[70] Stinson letter, p. 6

[71] PSPS interview, p. 12 (statement of Haynes); HHS, "Eliminating Racial and Ethnic Disparities in Health: Overview," p. 3, accessed at <http://raceandhealth.hhs.gov/over.htm>.

[72] HHS, "The Initiative to Eliminate Racial and Ethnic Disparities in Health," accessed at <http://raceandhealth.hhs.gov/>; HHS, "Eliminating Racial and Ethnic Disparities," p. 2.

[73] HHS, "Eliminating Racial and Ethnic Disparities," p. 2.

[74] *See* USCCR, *The Health Care Challenge*, vol. II, chaps. 3 and 4.

[75] HHS, "Eliminating Racial and Ethnic Disparities," p. 2.

[76] Ibid. *See* chaps. 2 and 3.

[77] HHS, "Eliminating Racial and Ethnic Disparities," p. 2.

Department recognizes that eliminating racial/ethnic disparities in the six areas will require new knowledge about the determinants of diseases and effective interventions for prevention and treatment.[78]

HHS will try to enhance the Nation's understanding of the causes of the disparities, as well as determine ways to reach individuals and communities who have not yet benefited from established interventions.[79] According to the Surgeon General, "This initiative is a major undertaking for HHS, and the goal may appear lofty and the strategy unclear, but it represents a much needed step toward improving the health status and health care for women and minorities."[80] HHS will provide leadership by conducting research, expanding or improving programs to deliver effective health services (clinical and preventive), reducing poverty, and providing children with safe and healthy environments.[81] As part of its efforts, HHS will collaborate with and strengthen its relationships with State, local, and tribal governments; communities and professional groups; and national and regional minority health and minority-focused organizations (including those that have the greatest access to and knowledge of minority communities), to address broader determinants of health, such as education, income, and environmental factors.[82]

The initiative's steering committee members will monitor HHS' current programs to determine how effectively resources are being used to eliminate health disparities, and they will recommend changes to enhance the impact of resources.[83] The committee will consult with minority community representatives and representatives from scientific and health services to determine how to reduce and ultimately eliminate racial/ethnic health disparities.[84] In addition, the committee will examine HHS' data, research agendas, services, and other interventions, and recommend changes to the Secretary so that health disparities are reduced by the beginning of the next century and eliminated by the year 2010—a goal that "parallels the focus" of the Healthy People 2010 initiative.[85] As an initial step to improve baseline data about the effectiveness of HHS' programs in reaching minority populations, HHS adopted a policy that requires all departmental data collection and reporting systems to include standard racial/ethnic categories.[86] This policy should enable HHS to determine if its recipients' programs are being delivered in a nondiscriminatory manner and to improve the availability of standard racial/ethnic data throughout operating divisions.[87]

In October 1998, the minority health coordinator in Region VI conducted the region's first meeting of the Interagency Working Group on Eliminating Racial and Ethnic Disparities. The group, represented by HHS staff from OCR, OGC, and operating divisions, was formed in response to the President's and HHS' initiative to eliminate the six major racial/ethnic disparities in health status by the year 2010. One of the goals of the group is to have direct and effective contact with communities and programs at the State and local levels that can contribute to this initiative. The Interagency Working Group will represent and implement Region VI's response to the Department's approach to eliminating disparities in health status. The minority health coordinator will lead the group in forming a plan of action.[88]

According to the Surgeon General, no one strategy can be used for eliminating health care disparities.[89] The Surgeon General stated:

> I am going to make a major effort to communicate the importance of this initiative . . . and if necessary, to embarrass people into communicating the magnitude of the problems that exist in this country in terms of disparities. To keep it at the forefront of Congress and everybody else, wherever I go I talk about it. I think the first major strategy is to communicate it—communicate it to them so that we can keep it in front of the American people, and then keep coming up

[78] Ibid., p. 5.

[79] Ibid., p. 2.

[80] Satcher interview, p. 2.

[81] HHS, "Eliminating Racial and Ethnic Disparities," p. 3.

[82] Ibid., p. 4.

[83] Ibid., p. 3.

[84] Ibid.

[85] Ibid., pp. 1–3.

[86] Ibid., p. 4. *See* USCCR, *The Health Care Challenge*, vol. II, chap. 4, for a discussion of HHS Data Council.

[87] HHS, "Eliminating Racial and Ethnic Disparities," p. 4.

[88] Ralph Rouse, regional manager, Region VI, OCR, HHS, memorandum to David Garrison, acting director, OCR (re: Monthly Significant Activities Report (SAR) for the Month of Oct. 1998), Nov. 10, 1998.

[89] Satcher interview, p. 2.

with new strategies every year. Whether they make it through Congress or not, keep going back with new efforts and new strategies.[90]

In a new effort to assist in closing the gap in health care outcomes for minorities, the Centers for Disease Control and Prevention (CDC) expects to publish a request for applications for the Racial and Ethnic Approaches to Community Health program (REACH 2010) during 1999.[91] REACH 2010, which is part of HHS' Initiative to Eliminate Racial and Ethnic Disparities in Health, is intended to help communities mobilize and organize their resources in support of effective and sustainable programs that will eliminate health disparities.[92] REACH 2010 will address disparities in health status in six health areas: infant mortality, diabetes, cardiovascular diseases, HIV, deficits in breast and cervical cancer screening management, and deficits in child and adult immunization.

REACH 2010 is a two phase 5-year program. Phase I will be a 12-month planning period to organize and prepare infrastructure for phase II. CDC will make available approximately $10 million in FY 1999 for the first phase.[93] Phase II will include the implementation of a demonstration project involving interventions for minority communities.[94]

Initiative on HIV/AIDS among Racial and Ethnic Minority Populations

In 1998 President Clinton and Secretary Shalala declared HIV/AIDS in racial and ethnic minority communities a severe and ongoing health care crisis.[95] This resulted in the creation of the Initiative to Address HIV/AIDS Among Racial and Ethnic Minority Populations as one segment of the larger Initiative to Eliminate Racial and Ethnic Disparities in Health. The purpose of the initiative, which was developed by HHS and the Congressional Black Caucus, is to reduce the disproportionate effect HIV/AIDS has on racial/ethnic minorities. HHS will spend $156 million (in addition to the $7 billion in HIV-related funding already administered by the Department) to provide grants to community-based organizations, research institutions, minority-serving colleges and universities, health care organizations, and State and local health departments.[96]

HHS has divided the $156 million among the Centers for Disease Control and Prevention, the Substance Abuse and Mental Health Services Administration (SAMHSA), the National Institutes of Health, the Health Resources and Service Administration, and the Office of Minority Health.[97] Over the next 3 years, these agencies will be responsible for awarding grants for programs dealing with HIV/AIDS prevention and education, research, faith-based initiatives, prison programs, treatment, bilingual/bicultural services, and other such projects.[98] Much of the focus of funding will be community-based, targeting specifically those minority communities that are most affected by the AIDS epidemic, in an effort to facilitate an understanding of the severity and prevalence of the disease, as well as risk factors. The director of HHS' Office of HIV/AIDS Policy stated:

> We have to have a concurrent strategy that focuses on changing the cultural context within the community in which individuals have to reveal themselves, and make that safe. . . . By targeting church leadership and organizations that do not have health as a centerplate issue, such as the National Urban League, NAACP, fraternities, sororities, and PTAs, those organizations can have HIV on their national agenda items and play a role in changing the way we react to and perceive HIV positive individuals in our communities.[99]

For example, both OMH and CDC are funding an HIV/AIDS program at a New York City-based organization, African Services Committee, Inc. (ASC), which will provide legal and undocumented immigrants and refugees from Africa, the Middle East, and the French-speaking Caribbean the help to overcome some of the

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[90] Ibid.

[91] "CDC Plans May Announcement for REACH 2010 Program," *Closing the Gap* (a newsletter of the Office of Minority Health, HHS), April 1999, p. 11.

[92] Ibid.

[93] Ibid.

[94] Ibid.

[95] Jennifer Brooks, "The Minority AIDS Crisis," *Closing the Gap*, April 1999, pp. 1–3. For a discussion on AIDS in minority communities, *see* chap. 2.

[96] Brooks, "The Minority AIDS Crisis," p. 2.

[97] Ibid., pp. 2–3.

[98] Ibid., p. 3.

[99] Ibid.

health obstacles they face.[100] Immigrants who do not have legal immigration status and work authorization are most often the ones with little or no health insurance, which reduces their chances of receiving adequate treatment, especially for HIV/AIDS.[101]

ASC devotes 50 percent of its efforts to fight HIV/AIDS, although it focuses on other communicable diseases, including sexually transmitted diseases and tuberculosis.[102] ASC built a program to train African peer staff to be skilled community health workers. ASC interpreters receive training provided by the New York Task Force on Immigrant Health before they are hired to work with clients.[103]

Similarly, with funding from several sources, including the OMH, Bienestar Human Services, Inc., of Los Angeles, California, has expanded its services to meet the needs of the Latino community.[104] Bienestar is the only organization based in the Latino community of Los Angeles that provides HIV/AIDS services.[105] The organization's HIV prevention programs target numerous individuals, including youth, women, gang members, substance abusers, gay/bisexual men, heterosexual Latino men, recent immigrants, and residents of housing projects. Bienestar offers treatment education and advocacy, self-help activities, and peer-to-peer counseling sessions to those who are HIV positive. The organization hopes to ensure that clients accept their HIV/AIDS diagnosis, go for medical care to treat the disease, and follow their treatment regimens.[106]

Minority Initiatives

According to Secretary Shalala, HHS has made efforts to "establish an infrastructure" that coordinates the development and implementation of four initiatives that are "governed in whole or in part" by Executive orders, including the Historically Black Colleges and Universities Initiative, the Hispanic Agenda for Action, and the Tribal Colleges and Universities Initiative.[107] During 1997, HHS inaugurated a fourth initiative to address the health and human service concerns of Asian Americans and Pacific Islanders.[108] On June 7, 1999, the President signed Executive Order 13125, Increasing Participation of Asian Americans and Pacific Islanders in Federal Programs.[109]

The Secretary's departmental Minorities Initiatives program consists of the Department Minority Initiative Steering Committee, which is comprised of agency operating division heads or their deputies, and the Department Minority Initiative Coordinating Committee, which is made up of representatives from all operating divisions and the staff offices.[110] The steering committee sets the policy, and the coordinating committee sets the policies in motion.[111] The Office of Minority Health was designated to provide oversight and staff support for both committees.[112]

Historically Black Colleges and Universities Initiative

The Executive order on the Historically Black Colleges and Universities (HBCUs) Initiative was originally issued in 1981 and was reissued in 1993.[113] The focus of the initiative is to provide financial assistance to historically black postsecondary schools and to black Americans at all education levels.[114] The initiative, which is administered by the Department of Education, includes strategies to strengthen HBCUs and

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[100] Jean Oxendine, "HIV/AIDS Program for New York's Immigrants," *Closing the Gap*, April 1999, pp. 6–7.

[101] Ibid., p. 6.

[102] Ibid.

[103] Ibid.

[104] Jean Oxendine, "L.A. Program Gives HIV Support Services, Education to Latino Community," *Closing the Gap*, April 1999, p. 7. Bienestar Services, Inc., was formed in 1989; its original goal was to help educate gay and bisexual men about HIV/AIDS. Ibid.

[105] Ibid.

[106] Ibid.

[107] Donna E. Shalala, Secretary, HHS, memorandum to Heads of Operating Divisions, Heads of Staff Divisions, and the Director of Intergovernmental Affairs (re: Structure for Coordinating Departmental Minority Initiatives), Oct. 19, 1998, p. 1 (hereafter cited as Shalala, Minority Initiatives Memo); PSPS interview, p. 14 (statement of Haynes).

[108] Shalala, Minority Initiatives Memo, p. 1.

[109] Exec. Order No. 13,125; 64 Fed. Reg. 31106–07 (1999).

[110] Stinson interview, p. 4.

[111] PSPS interview, p. 14.

[112] Shalala, Minority Initiatives Memo, p. 1.

[113] Exec. Order No. 12,876; 58 Fed. Reg. 58,735 (1993) (codified at 3 C.F.R., 1993 Comp., p. 671); PSPS interview, p. 14 (statement of Haynes).

[114] PSPS interview, p. 14 (statement of Haynes).

use new technologies to ensure their long-term viability.[115]

In the early 1990s, the U.S. Public Health Service established the HBCU Capacity Building program to increase HBCUs' involvement in health and social service programs sponsored by HHS. HHS claimed that HBCUs could compete more effectively for grant funds if they had "comprehensive and fully functional, sponsored program offices."[116] To examine the appropriateness of this program and its potential effect, OMH sent questionnaires to and conducted site visits at the participating HBCUs.[117] The study revealed that an established sponsored program office at each of the four HBCUs led to more "structured and uniform procedures" for managing externally sponsored programs.[118] As a result, some of the institutions increased their levels of proposal submissions.[119]

In September 1994, Secretary Shalala announced that 16 HBCUs had entered into a $4.25 million cooperative agreement to design, implement, and test a series of models aimed at reducing violence and alcohol and other drug abuse among minority individuals, families, and communities.[120] HHS stressed that HBCUs must be supported in their critical role in community development and advancement; the formation of the HBCU consortium reflected this commitment and implemented HHS' plans to sponsor community-based violence prevention activities.[121] The HHS Office of Minority Health sponsored the Minority Male Consortium for Family and Community Violence Prevention Program and a study to collect data on features of violence prevention programs at 13 HBCU family life centers, to determine approaches that could prevent or minimize violence committed on or by minority males.[122]

In 1995 the National Institute on Drug Abuse (NIDA) began offering current NIDA grantees 1-year supplements of $50,000 to increase opportunities for students and investigators at HBCUs to become involved in drug abuse research.[123] NIDA grantees are expected to offer research experiences so that participants can develop skills to conduct "rigorous drug abuse research" and expand NIDA's knowledge of cultural and ethical issues in drug abuse.[124]

Recognizing the importance and success of the initiative, HHS set a goal to target 3 percent of its available funds for institutions of higher education to HBCUs in 1998. According to an HHS document, despite declining budgets to most HHS agencies, the Office of Minority Health recommended an annual 15 percent increase in funding to HBCUs until the 3 percent goal is reached.[125]

Although overall there is relatively little participation of OCR regional offices in HBCU initiatives, a few regional offices have made an effort to participate in and contribute to various programs. OCR Region VII interacts with the African American community through its initiatives with the region's two HBCUs.[126] Despite the fact that there are no historically black colleges or universities in OCR Region I, the regional manager makes an effort to hire minority

[115] Exec. Order No. 12,876, § 1, 58 Fed. Reg. 58,735, 58,736 (1993) (codified at 3 C.F.R., 1993 Comp., p. 671).

[116] HHS, Project Abstract: Evaluation of the Cooperative Agreements for Demonstration Project for Capacity Building at Historically Black Colleges and Universities (HBCUs) FY 1992–1996, October 1998, accessed at <http://www.hhs.gov/progorg/aspe/pic/6/pic6246.txt>.

[117] Ibid.

[118] Ibid.

[119] Ibid.

[120] HHS, "$4.25 Million to Colleges for Violence Prevention Programs," press release, Sept. 14, 1994, accessed at <http://www.hhs.gov/news/press/pre1995pres/940914.txt>.

[121] Ibid.

[122] HHS, "Project Abstract: Evaluation of the Minority Male Consortium for Violence Prevention," July 1998, accessed at <http://www.hhs.gov/progorg/aspe/pic/9/pic57892.txt>. Note: HHS' Health Resources and Services Administration declared that family violence is a major public health concern. *See* HHS, Health Resources and Services Administration, "Office of Minority Health Projects and Initiatives," Mar. 20, 1997, p. 4, accessed at <http://www.hrsa.gov/hrsa/OMH/omhproj.htm> (hereafter cited as HRSA, "Minority Health Initiatives").

[123] HHS, National Institutes of Health, "Historically Black Colleges and Universities Initiative General Provisions for Administrative Supplements," *NIH Guide*, vol. 24, no. 2 (June 16, 1995), accessed at <http://www.nih.gov:80/grants/guide/1995/95.06.16/notice-historically-003.html>, p. 1.

[124] Ibid.

[125] HHS, Hispanic Agenda for Action, Steering Committee Meeting Summary, July 16, 1998, p. 4 (hereafter cited as HHS, Hispanic Steering Committee Meeting Summary).

[126] John Halverson, regional manager, Region VII, OCR, HHS, telephone interview, Feb. 12, 1999, p. 3.

college students as interns during the summer months.[127]

Hispanic Agenda for Action

HHS' Hispanic Agenda for Action was launched in 1996 based on recommendations from the departmental Working Group on Hispanic Issues to improve HHS' delivery of services to the more than 27 million Hispanic health care consumers, obtain input from the Hispanic community on HHS' policies and programs that affect them, and increase the number of Hispanic employees within HHS.[128] One of the key objectives of the initiative is to implement the 1994 Executive order that authorizes an overall multiagency effort on Hispanic education, coordinated by the Department of Education, similar to the HBCU initiative.[129] The Executive order directs Federal agencies to collectively make efforts to increase Hispanic American participation in Federal education programs and improve their educational outcomes.[130] According to the director of the Policy and Special Projects Staff, although the Executive order on educational excellence for Hispanics sets the basic parameters, HHS also has addressed issues of employment, customer service, health status, access to health care services, data, research, and other issues for Hispanic Americans.[131]

In September 1996, the Secretary of HHS established the Hispanic initiative's steering committee to monitor development of specific work plans for the nine elements on its action agenda.[132] The committee, chaired by the HHS Deputy Secretary, met four times to provide guidance and facilitate the implementation of the Hispanic Agenda for Action.[133] Nine objectives addressed for the Hispanic Agenda for Action were:

- Enhancing HHS' capacity to serve the Nation's Hispanics through strategies such as employing Hispanics and involving them in program planning, implementation, and evaluation.
- Implementing Executive Order 12900 on Educational Excellence for Hispanic Americans by means such as tracking and evaluating the level of funding awarded to Hispanic serving institutions for Hispanic health-related education and research programs.
- Improving collection and analysis of data covering Hispanics' use of inpatient, outpatient, and emergency health care services, including mental health.
- Tracking the progress of specific health status and health care issues that pertain to Hispanics residing in each HHS region.
- Enhancing Hispanics' involvement in research as investigators and participants in clinical trials and research studies.
- Promoting collaboration among operating divisions to address common goals and targeted populations.
- Purchasing Department supplies and consultation services from Hispanic-owned companies.
- Improving HHS' accessibility to Hispanic Americans by developing and disseminating guidelines to HHS' recipients on the needs of LEP populations.
- Appointing a departmental Hispanic steering committee to address the underrepresentation of Hispanics in the HHS work force.[134]

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[127] Caroline Chang, regional manager, Region I, OCR, HHS, telephone interview, Feb. 17, 1999, p. 13

[128] HHS, "Hispanic Agenda for Action: Improving Services to Hispanic Americans: One Year Progress Report," Feb. 8, 1999, accessed at <http://www.hhs.gov/about/heo/harp6.html#IX>, executive summary, p. 1 (hereafter cited as HHS, "Progress Report on Hispanic Initiative"); HHS, "Hispanic Health Leader Calls for Dialogue on Health Issues Facing Women of Color," press release, Feb. 12, 1997, accessed at <http://www.samhsa.gov/press/97/970711o.htm> (hereafter cited as HHS, Hispanic Initiative Press Release).

[129] HHS, "Progress Report on Hispanic Initiative," Section II: Implementing Executive Order 12,900: Educational Excellence for Hispanic Americans; HHS, Departmental Working Group on Hispanic Issues, "Hispanic Agenda for Action: Improving Services to Hispanic Americans," July 29, 1996, pp. 5–6, accessed at <http://waisgate.hhs.gov/cgi-bin/waigate?...cID=5943024392+34+0+0&WAISaction=retrieve> (hereafter cited as HHS, Report of Working Group on Hispanic Issues); Exec. Order No. 12,900, § 3, 59 Fed. Reg. 9,061 (1994) (codified at 3 C.F.R., 1994 Comp., p. 865).

[130] Exec. Order No. 12,900, § 6, 59 Fed. Reg. 9,061 (1994) (codified at 3 C.F.R., 1994 Comp., p. 865).

[131] PSPS interview p. 14 (statement of Haynes); *see* HHS, "Progress Report on Hispanic Initiative," p. 1.

[132] Shalala, Minority Initiatives Memo, p. 1

[133] HHS, "Progress Report on Hispanic Initiative," executive summary, p. 1.

[134] HHS, Report of Working Group on Hispanic Issues.

Currently, the work plans are being implemented in HHS operating divisions, and, according to the PSPS director, the initiative is growing on its own accord.[135] For instance, HRSA has established a goal to award 3 percent of its grants and contracts to Hispanic-serving institutions and health professions schools.[136]

In September 1997, HHS operating divisions and staff divisions held the National Hispanic Health Symposium, to explore a range of health issues affecting the Nation's Hispanic population, from the health of women and children to infectious diseases and cardiovascular health.[137] CDC, for example, used the symposium as a means to recruit Hispanics, disseminate health promotion and disease prevention literature in Spanish, and improve the operating division's understanding of Hispanics' health needs.[138] More than 550 leaders and representatives from Hispanic community organizations participated.[139]

At a 1998 Hispanic Agenda for Action steering committee meeting, the cochairperson of the Cultural Competency Subcommittee discussed a proposed customer service conference titled Improving Hispanic and Latino Customer Service—Working Toward a Culturally Competent, Inclusive Health and Human Services.[140] The conference addressed the nine elements (discussed above) on the initiative's "action agenda," and presented the best models on "capacity building" that can be replicated in HHS.[141]

Some of HHS' additional accomplishments regarding the Hispanic Agenda for Action (at the HHS headquarters level) include publishing and translating various departmental media materials into Spanish,[142] initiating Spanish language instruction for staff, developing a departmental Hispanic Web site, funding Hispanic conferences on health promotion and disease prevention, completing annual plans to comply with Executive Order 12900, adopting an HHS policy for improving the collection of race/ethnicity data, and appointing senior staff to the departmental Minority Initiatives Coordinating Committee to participate in crosscutting issues relevant to the Hispanic Agenda for Action.[143]

In July 1998, the Assistant Secretary for Management and Budget representative to the Hispanic Agenda for Action steering committee stressed that recruiting and retaining Hispanics and other minorities to HHS must be an ongoing effort.[144] Consequently, FDA, for example, is developing a "diversity databank" to identify and target Hispanic scientists and professionals for employment at HHS.[145]

Tribal Colleges and Universities Initiative

The Tribal Colleges and Universities (TCU) Initiative, established by Executive order in 1996, was modeled after the HBCU initiative.[146] The Department of Education also heads this initiative, and the Office of Minority Health has been designated as the lead within HHS. The TCU initiative addresses funding levels in education, from prekindergarten to adult education and at tribal colleges and universities.[147] Some of the objectives of the initiative are: (a) to ensure that tribal colleges and universities have greater recognition among accredited institutions, (b) to increase the level of Federal resources channeled

[135] PSPS interview, p. 14 (statement of Haynes); Shalala, Minority Initiatives Memo, p. 1.

[136] HRSA, "Minority Health Initiatives," p. 1.

[137] HHS, Hispanic Initiative Press Release.

[138] HHS, "Progress Report on Hispanic Initiative," section I.

[139] Ibid., p. 1.

[140] HHS, Hispanic Steering Committee Meeting Summary, pp. 1, 5.

[141] Ibid., p. 5.

[142] In the summer of 1998, NIH disseminated 450,000 copies of its Spanish publication *PRO SALUD* into Sunday newspaper supplements nationwide. *See* HHS, Hispanic Steering Committee Summary, p. 1.

[143] HHS, "Progress Report on Hispanic Initiative," pp. 1–2.

[144] HHS, Hispanic Steering Committee Meeting Summary, p. 2.

[145] Rosamelia Lecia, "FDA Supports HAA, Develops Diversity Databank," *Closing the Gap*, October 1998, p. 10.

[146] Exec. Order No. 13,021, 61 Fed. Reg. 54,929 (1996) (codified at 3 C.F.R., 1996 Comp., p. 221).

[147] PSPS interview, p. 14 (statement of Haynes); Exec. Order No. 13,021, 61 Fed. Reg. 54,929 (1996) (codified at 3 C.F.R., 1996 Comp., p. 221). Tribal colleges and universities are those institutions cited in section 532 of the Equity in Education Land Grants Status Act of 1994 (7 USC 301 note), any other institutions that qualify for funding under the Tribally Controlled Community College Assistance Act of 1978, Pub. L. No. 95–471, 92 Stat. 1325 (codified at 25 U.S.C. 1801–1815 (1994 & Supp. III 1997)), and Navajo Community College, authorized in the Navajo Community College Assistance Act of 1978, Pub. L. No. 95–471, title II, §§ 202–201, 92 Stat. 1329 (codified at 25 U.S.C. 640a note, 640c, 640c–1, 640c–1 note (1994). *See* Exec. Order No. 13,021, § 1, 61 Fed. Reg. 54,929 (1996) (codified at 3 C.F.R., 1996 Comp., p. 221).

to tribal colleges and universities, (c) to explore innovative approaches to integrate tribal post-secondary with early childhood, elementary, and secondary education programs, and (d) to support the National Education Goals.[148] The Executive order also fosters links between TCUs and private organizations.[149]

The tribal college movement began in the 1970s and, since that time, the number of TCUs has grown considerably. There are 30 tribal colleges in the Nation that serve more than 25,000 students from 250 Native American tribes. Most of these institutions are in the Midwest and Western States, such as North Dakota, South Dakota, Montana, and New Mexico. Before tribal colleges came into existence, many people living on reservations did not pursue higher education.[150] Those who did go to college attended mainstream universities and colleges, and their dropout rates were high. One of the reasons cited for this high dropout rate was that mainstream schools did not provide the support that Indian students needed to succeed.[151] The TCU initiative is a meaningful step toward bridging this gap. According to HHS, tribal colleges are centered around Native culture and offer nurturing programs that cannot be found elsewhere.[152]

Despite their vital role in blending academics and American Indian culture, tribal colleges have been consistently underfunded.[153] The White House initiative addresses this problem by requiring each agency within the Federal Government to develop a 5-year plan to boost both awareness of tribal colleges and access to Federal funding opportunities. Agencies must address ways to keep TCUs informed about funding opportunities; set annual goals for agency funds to be awarded to TCUs; and pinpoint areas of technical assistance that will be made available regarding the preparation of proposals for grants, cooperative agreements, and contracts.[154]

Agencies are at varying stages in their planning in this initiative and many do not understand the constraints of the TCUs.[155] Some agencies are asking schools for information about their needs all at once, which can be a burdensome request. Many agencies have become frustrated because the schools, which have been neglected for so long, have limited resources and cannot respond as quickly as the agencies would like.[156]

In response to the Executive order, OMH convened a working group to ensure that action plans related to this initiative set up a network of continuous support for tribal colleges.[157] HHS also plans to improve communication with TCUs by, among other means, making sure that TCUs know who their points of contact are within the Department. To increase academic and professional development opportunities for TCU students and faculty members, HHS plans to provide distance-based learning opportunities for TCUs, support the development of campus facilities, and provide schools with surplus property such as computers and furniture.[158]

On February 2, 1998, HHS held a meeting between its agency heads and tribal college presidents. According to HHS, the meeting provided both a valuable opportunity for face-to-face interaction and the opportunity for open discussions where the colleges could tell the Federal agencies what they need as opposed to vice versa.[159] Every agency within HHS is responsible for improving the health of American Indians and for strengthening the resources and capabilities of TCUS.[160] For example, the Health Resources Services Administration is planning grant workshops for TCUs and donating its sur-

148 Exec. Order No. 13,021, 61 Fed. Reg. 54,929 (1996) (codified at 3 C.F.R., 1996 Comp., p. 221). The National Education Goals set targets to be achieved by the year 2000 for the following areas: school completion; student achievement and citizenship; teacher education and professional development; mathematics and science achievement; adult literacy and lifetime learning; safe, disciplined, and alcohol- and drug-free schools; and parental participation. Pub. L. No. 103–227, title I, § 101, 108 Stat. 130 (1994) (codified at 20 U.S.C. § 5812(1)–(8) (1994).

149 *Id.*

150 Michelle Meadows, "Tribal Colleges and Universities," *Closing the Gap*, February 1998, p. 1.

151 Ibid.

152 Ibid.

153 Ibid.

154 Ibid.

154 Ibid.

155 Ibid., p. 2.

156 Ibid.

157 Ibid.

158 Ibid.

159 Ibid.

160 Ibid., p. 3.

plus computers. The Agency for Health Care Policy and Research (AHCPR) plans to increase awareness among TCU students about careers in health services research.[161] The Agency for Toxic Substances and Disease Registry (ATSDR) has committed funding for a conference on TCU capacity building.[162] The Centers for Disease Control and Prevention is planning to work with TCUs on developing disease prevention materials for American Indians/Alaska Natives.[163] The National Institutes of Health is looking for ways to bring TCU science faculty to NIH for temporary assignments.[164]

Asian American and Pacific Islander Initiative

In June 1997, HHS established the Asian American and Pacific Islander (AAPI) Initiative in response to concerns expressed by AAPI community groups and recommendations from recent national AAPI health conferences.[165] HHS established a departmental working group (including staff from the Office for Civil Rights, the Office of Minority Health, and HHS staff divisions and operating divisions) to review the issues and develop an action agenda for improving the effectiveness and relevance of the initiative's services and programs.[166] Members of the working group held more than 25 meetings nationwide to get input from the Asian/Pacific Islander community.

The working group has established goals in six functional areas:[167]

- Goal 1 is to improve the health and well-being of the APPI population by increasing access to health care and human services.
- Goal 2 is to increase and improve collection, analysis, and dissemination of data about the AAPI population and subpopulations.
- Goal 3 is to increase the number of funded projects and programs targeting the AAPI population.
- Goal 4 is to increase outreach to and participation of AAPI populations in HHS or HHS-sponsored training programs.
- Goal 5 is to ensure that issues affecting underserved AAPI populations are addressed through their representation in the HHS work force and participation in HHS operations.
- Goal 6 seeks crosscutting collaboration to enhance HHS customer service to the AAPI population, enhancing HHS' capacity to serve Asian Americans.[168]

During FY 1998, there were many AAPI activities under each goal that were designed and are currently being implemented. Under goal 1, the Health Care Financing Administration is piloting a mammography screening project in one of its regions that will identify and mobilize existing community resources to improve access of AAPIs to health care services. HCFA also has a pilot project in Boston's Chinatown to inform the community of the hepatitis B vaccination, available through medicaid and medicare.[169] Also under goal 1, the Centers for Disease Control and Prevention is developing strategies to ensure that AAPI women receive regular cancer screening.[170] The Office on Women's Health funded additional centers for women's health services, programs, and education that target members of Asian American subgroups.[171]

The Substance Abuse and Mental Health Services Administration, in collaboration with the Asian and Pacific Islander American Health Forum is issuing several "minigrants" to community organizations to provide technical assistance to providers of mental health and substance abuse services for AAPIs.[172] The Office of Minority Health will support community health coalitions that include AAPIs and support at least two cooperative agreements with Asian American and Pacific Islander organizations to identify gaps in services, and to carry out activi-

[161] Ibid.

[162] Ibid.

[163] Ibid.

[164] Ibid.

[165] HHS, "Overview: HHS Asian American and Pacific Islander Action Agenda," Mar. 29, 1999, pp. 1, 5, accessed at <http://www.ombre.gov/overview2.htm> (hereafter cited as HHS, "AAPI Action Agenda").

[166] Ibid., pp. 1–3.

[167] Ibid., pp. 2–3.

[168] Ibid.

[169] Ibid., pp. 5–6.

[170] Ibid., p. 6.

[171] Ibid.

[172] Ibid.

ties to increase knowledge and understanding of health risk factors.[173] The Health Resources and Services Administration is developing two monographs that will describe methods for improving HIV-related services to members of the community, as well as activities that address the Asian American languages and cultural components in providing adequate health services.[174]

Under goal 2, various departmental components began collaborating to update directories and other data resources to expand information about AAPIs. For example, HHS survey data on AAPI mortality rates by States and the District of Columbia are now made available.[175] Under goal 3, several components in HHS, including NIH and the Agency for Health Care Policy and Research conducted research projects and awarded grants that target members of the Asian American communities. CDC developed and identified strategies to ensure AAPI cultural sensitivity and community participation in its research projects.[176]

Under goal 4, HRSA offered training to its constituents and service providers on delivering culturally competent care to AAPI communities, and training to AAPI clinicians to enhance their participation in the field. Other operating divisions offered training, training data and information, as well as education programs for AAPI health care workers.[177]

Under goal 5, in addition to enhancing departmental recruitment and hiring of members of the AAPI population, particularly at the senior level, the initiative includes a component whereby the Office of Minority Health and the Food and Drug Administration are developing the opportunity for AAPI members to serve on advisory council positions, review bodies, and consumer panels. The Office on Women's Health is developing a data bank of AAPI women contacts and resumes for various positions and advisory boards.[178] Under goal 6, HHS collaborated with the Congressional Asian Pacific Caucus and held a women's summit meeting in July 1998, with the objective of increasing the number of AAPI caucus participants.[179]

HHS/OCR issued guidance to staff on enforcement of title VI of the Civil Rights Act of 1964[180] with respect to the obligations of HHS grantees to ensure that persons with limited English proficiency (LEP) have equal opportunity to participate in programs.[181] OCR plans to provide regional technical assistance to State and local agencies that administer HHS-funded activities to identify the concerns of AAPI populations. OCR will host regional meetings to address the needs of the AAPI population in both urban and rural areas and in areas with large Asian American and Pacific Islander populations.[182]

In June 1999, the President issued an Executive order aimed at increasing the participation of Asian Americans and Pacific Islanders in Federal programs.[183] The Executive order established a President's Advisory Commission on Asian Americans and Pacific Islanders within HHS and created an interagency working group on Asian Americans and Pacific Islanders. The President's Advisory Committee is responsible for advising the President on:

> (a) the development, monitoring, and coordination of Federal efforts to improve the quality of life of Asian Americans and Pacific Islanders through increased participation in Federal programs where such persons may be underserved and the collection of data related to Asian American and Pacific Islander populations and sub-populations; (b) ways to increase public-sector, private-sector, and community involvement in improving the health and well-being of Asian Americans and Pacific Islanders; and (c) ways to foster research and data on Asian Americans and Pacific Islanders, including research and data on public health.[184]

The Executive order also requires each executive department, and agencies designated by the Secretary of HHS, to prepare a plan to improve the

[173] Ibid., pp. 6–7.

[174] Ibid.

[175] Ibid., pp. 8–9.

[176] Ibid., p. 10.

[177] Ibid., pp. 10–11.

[178] Ibid., p. 12.

[179] Ibid., pp. 13.

[180] Pub. L. No. 88–352, tit. VI, 78 Stat. 252 (codified as amended at 42 U.S.C. §§ 2000d–2000d–7 (1994)).

[181] *See* HHS, OCR, "Guidance Memorandum: Title VI Prohibition Against National Origin Discrimination—Persons with Limited English Proficiency," Jan. 29, 1998.

[182] HHS, "AAPI Action Agenda," p. 14.

[183] Exec. Order No. 13,125; 64 Fed. Reg. 31105–07.

[184] *Id* at § 2.

quality of life of Asian Americans and Pacific Islanders through increased participation in Federal programs. These plans will be integrated into a governmentwide plan.[185]

HHS Operating Divisions' Initiatives and Programs

Operating divisions are the primary source of funding for recipients of Federal health care grants, and they control the majority of the resources allocated for research.[186] Thus operating divisions play a critical role in the development and implementation of initiatives, programs, and research projects. Despite the lack of funds specifically designated to minority and women's health programs, and the operating divisions' apparent reluctance to incorporate civil rights into their daily operations, many operating divisions have instituted innovative and effective initiatives that target women and minorities.

OCR Initiatives with Operating Divisions

The Department's minority and other initiatives have the potential to provide a fair amount of interaction between OCR and the operating divisions. According to one OCR official, staff work together on steering and coordinating committees on the Hispanic Agenda for Action and the tribal colleges and universities and historically black colleges and universities initiatives.[187] Operating divisions and OCR managers also participate in work groups for other initiatives, such as one addressing disparities in the quality of care received by racial/ethnic minorities, and Healthy People 2000 and 2010.[188] Although many of the departmental initiatives have a formal structure that brings OCR and operating division staff together, some of the interaction has been initiated by OCR. In 1998 OCR began a partnership to address issues related to limited English proficiency (LEP) and the Hill-Burton program, which led to more frequent contact with operating divisions.[189]

Some OCR staff reported that their office works more frequently with some operating divisions, such as Administration for Children and Families, HCFA, and HRSA.[190] OCR works with these entities to address issues relating to health care access such as waivers and managed care, improving access to health care facilities, as well as the Children's Health Insurance Program, and the Healthy People 2000 and 2010 activities.[191] ACF is working with OCR on a draft compliance document on the Multiethnic Placement Act of 1994[192] to ensure that OCR's civil rights compliance and enforcement responsibilities do not conflict with ACF's program requirements, and vice versa.[193] OCR staff also have worked with HCFA to create civil rights policy statements[194] and to provide civil rights training

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185 *Id.* at §§ 4–5.

186 *See* USCCR, *The Health Care Challenge*, vol. II, chap. 5, for more information on the organization, structure, and civil rights activities of the operating divisions. In response to the Commission's request for information, six HHS operating divisions included materials on minority and women's health initiatives in their submissions: NIH, HCFA, HRSA, SAMHSA, CDC, and FDA. Although the Administration for Children and Families did not submit materials, its Office of Refugee Resettlement (ORR) has published numerous studies that enhance the public's awareness on Asian refugee's health needs. ORR works with traditional health care agencies, from the national to local levels, to improve service accessibility and expand their provisions specifically to meet refugees' health needs. Dennis Hayashi, director, OCR, HHS, letter to Frederick D. Isler, then acting assistant staff director for Civil Rights Evaluation, USCCR, June 16, 1995 (re: recommendations of U.S. Commission on Civil Rights, *Civil Rights Issues Facing Asian Americans in the 1990s*) (hereafter cited as HHS, response to recommendations cited in *Civil Rights Issues Facing Asian Americans in the 1990s*).

187 PSPS interview, p. 14 (statement of Haynes).

188 Ibid.

189 Ibid., p. 36 (statement of Haynes).

190 O'Brien and Mackey interview, p. 8 (statement of O'Brien); PSPS interview, pp. 36–37 (statement of Haynes).

191 OCR July 29, 1998, interview, p. 3 (statement of Copeland); O'Brien and Mackey interview, p. 8 (statement of O'Brien); PSPS interview, pp. 36–37 (statement of Haynes).

192 Pub. L. No. 103–382, 108 Stat. 3518 (codified in scattered sections of 7, 8, 15, 20, 25, 29, and 42 U.S.C. (1994 & Supp. III 1997)).

193 PSPS interview, p. 35 (statement of Haynes).

194 HCFA approached OCR for assistance with its policy statement. Kathleen O'Brien, special assistant to the director, and Patricia Mackey, deputy director; Valita Shepperd, deputy director, Program Development and Training Division; Ronald Copeland, associate deputy director; Johnny Nelson, deputy director, Voluntary Compliance and Outreach Division; Toni Baker, director, Investigations Division, Office of Program Operations, OCR, HHS, interview in Washington, DC, Nov. 13 and 18, 1998, pp. 17, 18 (statement of Copeland) (hereafter cited as OPO interview); PSPS interview, pp. 28–29 (statement of Haynes). *See* Ramon Suris-Fernandez, director; Roderick Locklear, EEO manager; Alexia Redd, EEO specialist, Office of Equal Opportunity and Civil Rights; and Joe Tilghman, regional administrator, Region VII, Health Care Financing Administration, HHS, telephone interview, Apr. 9, 1999, p. 2 (statement of Locklear) (hereafter cited as HCFA OEOCR

to HCFA staff in 1999.[195] OCR also developed a civil rights policy statement with PHS several years ago.[196]

Operating division staff did not report their interactions with OCR as being as frequent or regular as OCR staff indicated. Some of the recent increase in interaction between OCR and the operating divisions may be because many operating divisions have expanded their EEO offices to include extramural civil rights components and have begun to negotiate for additional responsibilities through memoranda of understanding. For example, SAMHSA and HCFA have recently added extramural civil rights responsibilities to their equal opportunity offices,[197] and FDA and HCFA anticipate signing memoranda of understanding with OCR.[198]

National Institutes of Health

The National Institutes of Health (NIH) is the primary biomedical health research agency of the Federal Government.[199] NIH has 22 centers and institutes focusing on different areas of health research. NIH administers many programs of special interest to underrepresented minorities.[200]

In 1994 NIH revised its research inclusion policy to meet the specific mandate of the NIH Revitalization Act of 1993[201] that women and minorities be included in all of its clinical research studies.[202] Specifically, the revised guidelines reinforce previous NIH policies with four major differences:

- That NIH ensure that women and minorities and their subpopulations be included in all human subject research.
- That women and minorities and their subpopulations be included in extramural Phase III clinical trials in numbers adequate to allow for valid analyses of differences in intervention effect.
- That cost is not allowed as an acceptable reason for excluding these groups.
- That NIH initiate programs and support for outreach efforts to recruit and retain women and minorities and their subpopulations as volunteers in clinical studies.[203]

To ensure universal adherence to the revised inclusion guidelines, NIH conducted extensive training for approximately 1,000 NIH staff. Staff, in turn, explained the requirements to applicants, reviewers, and others. NIH also sponsored outreach activities to explain the guidelines to the scientific and nonscientific communities, and issued an outreach notebook that outlines the importance of recruitment and retention of women and minorities as human subject volunteers in research.[204]

Office of Research on Minority Health

The Office of Research on Minority Health (ORMH) was established in August 1990, because both Congress and NIH recognized that there was a gap in the health care provided for minorities and nonminorities.[205] ORMH's mission is to seek ways of extending healthy life and reducing the burden of illness among minorities through targeted research and to expand the participation of underrepresented minorities in

interview); Bruce C. Vladeck, administrator, Health Care Financing Administration, HHS, memorandum to HCFA Leadership, Oct. 20, 1994 (re: HCFA Civil Rights Compliance Policy Statement); Nancy-Ann Min DeParle, administrator, Health Care Financing Administration, HHS, memorandum to HCFA Leadership, HCFA Civil Rights Compliance Policy Statement, Apr. 9, 1998.

[195] OPO interview, p. 17 (statement of Copeland); HCFA OEOCR interview, p. 7 (statement of Suris-Fernandez).

[196] PSPS interview, p. 29 (statement of Haynes).

[197] OPO interview, p. 13 (statement of Copeland); HCFA OEOCR interview, p. 2 (statement of Locklear).

[198] Rosamelia T. Lecea, director, and Rosa Morales, deputy director, Office of Equal Employment and Civil Rights, Food and Drug Administration, HHS, telephone interview, Mar. 8, 1999, pp. 1–2.

[199] Ruth L. Kirschstein, deputy director, National Institutes of Health, HHS, letter to Frederick D. Isler, assistant staff director for Civil Rights Evaluation, USCCR, Jan. 22, 1999 (re: request for information) (hereafter cited as NIH, Response to Information Request).

[200] Ibid.

[201] Pub. L. No. 103–43, 107 Stat. 122 (codified in scattered sections of 8, 21, and 42 U.S.C. (1994 & Supp. II 1996).

[202] 42 U.S.C. § 289a–2 (1994). HHS, National Institutes of Health, Office of Research on Women's Health and NIH Tracking/Inclusion Committee, *Implementation of the NIH Guidelines on the Inclusion of Women and Minorities As Subjects in Clinical Research Trials*, December 1998, p. 1 (hereafter cited as NIH, *Implementation of NIH Guidelines*).

[203] NIH, *Implementation of NIH Guidelines*, p. 1.

[204] Ibid., pp. 1–2.

[205] John Ruffin, director, Office of Research on Minority Health, National Institutes of Health, HHS, telephone interview, Apr. 13, 1999, p. 1 (hereafter cited as Ruffin interview).

all phases of biomedical and behavioral research.[206]

To accomplish its mission, ORMH uses its budget and the Minority Health Initiative.[207] The ORMH budget is dedicated to office operations and to outreach and collaborative activities and programs with the NIH institutes and centers in areas such as educating minority communities about important NIH policies and programs, conducting technical assistance workshops, supporting national conferences on minority health issues, convening advisory committee meetings, and supporting the NIH minority research supplement programs.[208] The Minority Health Initiative, which is administered by the ORMH and implemented in collaboration with the various NIH institutes and centers, is a comprehensive program with a focus on interventions that will reduce the disproportionate burden of disease among minority populations.[209]

While the office has no interaction with HHS/OCR, the director of ORMH is an active participant on a number of operating division committees and ORMH also works collaboratively with NIH entities, such as the Office of Research on Women's Health, and other Federal agencies.[210] In addition, ORMH provides or transfers funds from its budget to support grants administered out of the OMH.[211]

Working with the NIH institutes and centers, ORMH focuses on supplementing existing initiatives to ensure the inclusion of minorities, funding or cofunding new and continuing initiatives that focus on racial and ethnic minorities, and piloting new initiatives in important areas where gaps have been identified and in which no studies or activities are being sponsored by the institutes and centers.[212] Although ORMH can initiate and fund programs under the Minority Health Initiative, it, like all of the offices in the Office of the Director, does not have grant-making authority.[213] Such authority is limited to the individual institutes and centers, which require, as an integral part of the award of grants, mechanisms for peer review for scientific merit. Such review is based primarily on guidelines from the Center for Scientific Review.[214]

The ORMH does more than coordinate, monitor, and report on minority initiatives. The office has an $80 million budget, which includes approximately $70 million from the Minority Health Initiative, used to support programmatic activities implemented in partnership with the NIH institutes and centers.[215] Priority setting is accomplished through a consultative process, which involves grassroots community organizations, research scientists, minority educators, and the institutes and centers.[216] Any identified gaps serve as a basis for new minority health related initiatives that are developed by the ORMH in consultation with the relevant institutes and centers. Congressional reports and departmental directives are also considered in priority setting.[217] The ORMH communicates its priorities to the institutes and centers annually; in turn, the institutes and centers submit a number of projects for consideration for support. Although the ORMH has shared fiscal authority for those initiatives that it either funds or cofunds; the institutes and centers decide the overall level of funding that a program receives. It is anticipated that the institutes and centers eventually will assume total fiscal responsibility for those pilot programs that are determined to be successful.[218]

Evaluating the success of NIH-supported programs has proved difficult, particularly with regard to funding minority institutions.[219] Some HBCUs, TCUs, and other minority-serving institutions of higher education have complained that funding levels and release time allocations for research projects generally have been insufficient. In particular, the HBCUs believe that the amount of funding provided is not enough to

[206] Ibid., p. 1.

[207] Ibid., p. 2.

[208] Ibid., p. 3.

[209] Ibid.

[210] Ibid., p. 5.

[211] Ibid., p. 4.

[212] Ibid., p. 3.

[213] Ibid.

[214] Ruth L. Kirschstein, deputy director, National Institutes of Health, HHS, letter to Frederick D. Isler, assistant staff director for Civil Rights Evaluation, USCCR (re: information for health care report), July 2, 1999, attachment, p. 2.

[215] Ruffin interview, p. 2.

[216] Ibid., p. 3.

[217] Ibid.

[218] Ibid.

[219] Ibid.

make them successful.[220] Therefore, minority institutions have asked that restrictive release time allocations and funding levels be reassessed.[221] With sufficient funding, minority-serving institutions believe they can be successful in the health research enterprise.[222]

Lack of infrastructure, including the quality or availability of laboratories and research facilities, presents another problem for minority academic institutions.[223] A school's ability to compete for funds can be determined by its infrastructure, especially in clinical research. According to the director of the ORMH, the infrastructure issue in research is very much like competitive athletics.[224] For example, the infrastructure for sports varies from school to school. Division I and Division II schools cannot compete at the same level because the expenditures and facilities are different. This has been one of the complaints from HBCUs.[225] Currently, majority institutions out-compete the minority institutions (because minority institutions traditionally have been underfunded) resulting in an unequal playing field.[226]

The idea of "leveling" to meet the needs of certain communities is not new.[227] Both the NIH Small Business Innovation Research and the Small Business Technology Transfer Research Programs were put in place to provide small businesses with an opportunity to participate in Federal small business innovation research programs.[228] NIH developed an Academic Research Enhancement Award to create research opportunities for scientists and institutions otherwise unlikely to participate extensively in NIH programs.[229] This program was an attempt at leveling that did not go quite far enough because it did not make a distinction among eligible institutions of higher learning in terms of their infrastructure and capacity or academic and/or research potential.[230] Numerous programs go an additional step to achieve the leveling phenomenon.[231] For example, title III of the Higher Education Act of 1965, administered by the Department of Education, provides funding and assistance to institutions of higher education with limited financial resources serving a high percentage of economically disadvantaged students.[232] According to the act:

> [T]here is a particular national interest in aiding those institutions of higher education that have historically served students who have been denied access to postsecondary education because of race or national origin and whose participation in the American system of higher education is in the Nation's interest so that equality of access and quality of postsecondary education opportunities may be enhanced for all students.[233]

Unlike the competitive programs at NIH or even other programs at the U.S. Department of Education, title III programs provide funding to all institutions that meet basic eligibility.[234]

To assist the Secretary of HHS with implementing the three minority initiative Executive orders that focus on leveling the playing field for minority institutions, the ORMH has recommended a hybrid of the Small Business Innovation Research and title III program models.[235] Such a model would establish programs for which only institutions recognized under the

[220] Ibid.

[221] Ibid.

[222] Satcher interview, p. 12.

[223] Ibid.

[224] Ruffin interview, p. 4.

[225] Ibid.

[226] Ibid.

[227] John Ruffin, director, Office of Research on Minority Health, National Institutes of Health, HHS, fax to Margaret Butler, Office of Civil Rights Evaluation, USCCR, Apr. 13, 1999 (re: Leveling the Playing Field) (hereafter cited as Ruffin, Leveling the Playing Field).

[228] Ibid., pp. 1–2.

[229] Ibid., p. 2.

[230] Ibid.

[231] Ibid.

[232] Pub. L. 89–239, title III, 79 Stat. 1229 (codified as amended at 20 U.S.C. 1051–1068) (1994 & Supp. III 1997)). *See* Ruffin, Leveling the Playing Field, p. 3.

[233] 20 U.S.C. § 1051(a)(7) (1994).

[234] Ruffin, Leveling the Playing Field, p. 3. In their applications, institutions must describe how they will develop "a comprehensive development plan to strengthen the institution's academic quality and institutional management. . ."; must set forth policies and procedures describing how the funds received will be used to further the purposes of the act; and must set forth policies and procedures for evaluating the effectiveness of the program to be funded. 20 U.S.C. § 1066(b)(1), (b)(2), (b)(7) (1994).

[235] Ruffin, Leveling the Playing Field, p. 4; Exec. Order No. 12387, Historically Black Universities and Colleges; Exec. Order No. 12900, Educational Excellence for Hispanic Americans; Exec. Order No. 13021, Tribal Colleges and Universities.

Executive orders would be eligible to compete.[236] Fair competition would be ensured through the design and development of "peer group specific programs."[237] According to the director of ORMH, each peer group would apply to competitive, targeted programs that support the mission of the sponsoring agency, but that are also responsive to the needs, missions, and potential of the applicant institutions as well.[238] A model of this nature recognizes the importance of empowering racial and ethnic minorities to become full participants in improving their health, while at the same time recognizing the role that all institutions of higher learning can play in alleviating health disparities and improving the overall health of America. In response to the director's recommendation, a committee with representation from selected operating divisions is being assembled to develop this concept further as well as create an implementation plan.[239]

ORMH also believes that professors at minority institutions should be encouraged to remain active in research.[240] NIH funds several programs, such as the Minority Biomedical Research Support Program, that help minority professors get back into research which in turn will help minority institutions become more competitive for research funds.[241] According to the director of ORMH, professors with excellent research training often lose their competitive edge in research due to heavy teaching demands and inadequate research infrastructure. With the assistance of NIH capacity building programs, one of the challenges to maintaining a competitive research edge at minority institutions can be effectively addressed.[242]

Aside from partnering with the NIH institutes and centers, ORMH also works directly with HBCUs, tribal colleges and universities, and Hispanic-serving institutions to expand the participation of underrepresented minorities in all phases of biomedical and behavioral research by developing collaborative research and research training programs between minority and majority institutions and increasing the competitiveness of minority scientists in securing research support.[243] The director of ORMH believes that a strong minority presence in the health research work force is an important element in closing the gap in health disparities.[244]

Because the director of ORMH believes that enhancing minority interest in biomedical and related research must begin before students reach college,[245] ORMH is involved in a modest ($3 million) K–12 mathematics program with the National Science Foundation. The program focuses on mathematics and engineering, although ORMH would like to see it expanded to include the life sciences.[246]

The director of ORMH described other initiatives and minority concerns that are addressed throughout NIH. For example, a particular concern of the Asian American and Pacific Islander community is the lack or paucity of data on members of this group. NIH is beginning to work with Asian American organizations to ensure the appropriate data are collected. The agency is beginning to collect data on many Asian American subgroups, such as Vietnamese, Filipino, Chinese, and Korean Americans. One project that is being funded through the HHS' OMH and the NIH National Cancer Institute focuses on Asian American and Pacific Islander women and cervical cancer.[247]

Although ORMH does not specifically address gender issues, some minority women initiatives are supported by the office. There are, however no collaborative projects underway that require joint fiscal support from the ORMH and the Office of Research on Women's Health.

Office of Research on Women's Health

The Office on Research on Women's Health (ORWH) was established in 1990 and was the first office concerned with women's health to be established in HHS.[248] Its director is also the

[236] Ruffin, Leveling the Playing Field, p. 4.

[237] Ibid.

[238] Ibid.

[239] Ibid.

[240] Ruffin interview, p. 4.

[241] Ibid.

[242] Ibid.

[243] Ibid.

[244] Ibid., p. 3.

[245] Ibid., p. 5.

[246] Ibid.

[247] Ibid., p. 3.

[248] Pub. L. No. 103–43, § 141(a)(3), 107 Stat. 136 (1993) (codified at 42 U.S.C. § 287d (1994 & Supp. II 1996)); Vivian Pinn, director, Office of Research on Women's Health, National Institutes of Health, HHS, telephone interview, Apr. 13, 1999, p. 1 (hereafter cited as Pinn interview).

associate director of NIH for Research on Women's Health.[249] The ORWH has three major functions: to ensure that women are included in clinical research; to increase research on women's health, set a research agenda in that area, and prioritize the issues; and to increase opportunities for recruitment and retention of women in biomedical careers.[250]

The ORWH grew out of a U.S. General Accounting Office (GAO) investigation on the lack of women in clinical trials.[251] In response to the GAO report and later the Revitalization Act of 1993, NIH changed its policies to include women and minorities in clinical research and developed a system to track the number of women and minorities included in NIH research.

The ORWH's budget, which is part of the budget of the Office of the Director, is determined by NIH's director.[252] Fifteen percent of ORWH's budget is allocated to operations and the remaining 85 percent goes to programs.[253] Of that 85 percent, approximately 80 percent is put into research.[254]

The ORWH works with three committees to accomplish its goals. The Tracking Committee works on inclusion issues and has representatives from each of NIH's institutes. The Coordinating Committee also has representatives from each of NIH's institutes and, according to the director of ORWH, is a valuable means by which the ORWH can exchange information and get cooperation for developing programs. The third committee is an outside advisory committee consisting of 18 members who are not Federal employees. The three committees advise ORWH on agendas, programs, and research for women.[255]

The ORWH does not review grant applications.[256] Each institute is responsible for reviewing the grants submitted to it, and inclusion of women in research is part of the normal peer review of the scientific merit of grant proposals. The Center for Scientific Review sets up the study sections for the scientific reviews of grant applications.[257]

All grant applications must indicate which populations (based on gender, race, and ethnicity) will be included in the study.[258] The purpose of the study dictates whether particular groups can be excluded. If the study is on a condition that affects women or minorities, then women or minorities must be included in the study or else sufficient justification must be given for not including them.[259] For example, men could be excluded from a study of the effect of aspirin on heart disease because that research has already been done on male subjects. If women or minorities are excluded from a study design without adequate justification, then a "bar to funding" is issued for that research proposal.[260] ORWH provided the Commission a report on the implementation of the NIH guidelines on the inclusion of women and minorities in clinical research, which identifies the number of proposals that were issued a bar to funding either for unacceptable gender inclusion or unacceptable minority inclusion.[261] The report also shows the number of extramural awards where the bar to funding was lifted and the reasons why it was lifted.[262] The institute cannot fund any application with a bar to funding until the bar is removed.[263] According to the director of ORWH, in many instances, a bar was imposed because the investigators failed to provide information on the inclusion of minorities and women, but once the information was provided, the bar was lifted. Some proposals were rejected because of failure to follow the inclusion guidelines.[264]

A progress report for ongoing studies, showing the number of people enrolled in the study by race/ethnicity and gender, must be submitted each year by researchers receiving funding. If a study does not carry out the proposed inclusive enrollment, the study funding can be in jeopardy. Program managers received training about

249 Ibid.

250 Ibid., p. 2.

251 Ibid.

252 Ibid., p. 6.

253 Ibid.

254 Ibid.

255 Ibid., p. 2.

256 Ibid.

257 Ibid., pp. 2–3.

258 Ibid., p. 3.

259 Ibid.

260 Ibid.

261 NIH, *Implementation of NIH Guidelines*, p. 5. *See* Pinn interview, p. 3.

262 NIH, *Implementation of NIH Guidelines*, pp. 6–7.

263 Pinn interview, p. 3.

264 Ibid.

their inclusion responsibilities when guidelines were changed in 1994.[265] Program managers continue to be trained through e-mail and meetings.[266] The Extramural Program Management Committee is another way in which program managers are informed of their inclusion responsibilities. The ORWH also uses both the Tracking Committee and the Coordinating Committee to make sure that the institutes are informed about the inclusion guidelines. In 1999 the director proposed another series of training meetings on this matter and found that training was not needed.[267] The ORWH also has met with chairs and representatives of institutional review boards to discuss and encourage their responsibility for inclusion as well as protection of research subjects and informed consent.

The Revitalization Act requires that NIH prepare a biennial report on compliance with the inclusion guidelines.[268] In the report, each of the NIH institutes' advisory committees indicates that it has ensured its institute is in compliance with the inclusion guidelines.[269] A biennial report was completed in 1997 and ORWH will issue the next report in 2000. The director of ORWH expects that by asking the institutes to certify their compliance and by providing ORWH with data, the institutes will continue to have internal reviews of inclusion matters.[270]

The Tracking Committee provides the ORWH with a liaison from each of the institutes and spreads accountability for following the inclusion guidelines as a NIH-wide activity. The Tracking Committee monitors the report on implementation of the guidelines, which is compiled through the computerized tracking system in the Office of Extramural Research.[271] The ORWH pulls together the aggregate data for this report to monitor compliance, facilitates the collection of this information across institutes, and makes sure that the agency is on top of the issues.

The ORWH promotes and funds research and performs educational outreach. The office also issues biannual reports on NIH institutes' major initiatives and research on women's health. The ORWH is in the process of completing a seven-volume report to be released in 1999. The report assesses NIH progress on research on women over the past 10 years, identifies current gaps in research on women, and suggests innovative ways to address women's health needs.[272] The ORWH convened a task force and held public meetings and hearings involving more than 2,000 scientists, practitioners, and policymakers to compile this report.

Although ORWH funds research, it does not have direct funding authority.[273] All of the funding goes through the institute supporting the research. The ORWH works with the various NIH institutes to help cofund research, but the majority of the funding comes from the institutes. ORWH has cofunded projects with the National Institute of Child Health and Human Development, the National Institute of Mental Health, and the National Cancer Institute.[274] For example, a project with the National Cancer Institute will develop a test for the virus that causes cervical cancer, a leading cause of cancer death of women worldwide. ORWH has also funded joint projects with other operating divisions, such as the Food and Drug Administration and the Agency for Health Care Policy and Research; and with other Federal agencies such as the National Science Foundation. For example, the National Science Foundation has a project called Professional Opportunities for Women in Research and Education aimed at lessening the underrepresentation of women in the science work force, and to provide female scientists with funding for projects that otherwise might remain unfunded. ORWH is particularly interested in the underrepresentation of women in biomedical research.[275]

The ORWH funds many projects to increase the recruitment and retention of women in biomedical careers. Concerns that programs could not be targeted strictly to women have sometimes inhibited program development. For example, the ORWH designed and implemented a reentry program for scientists who had career interruptions, but was told it could not target

265 Ibid.

266 Ibid.

267 Ibid.

268 42 U.S.C. § 289a–2(f) (1994); Pinn interview, pp. 3–4.

269 Pinn interview, p. 4.

270 Ibid.

271 Ibid.

272 Ibid.

273 Ibid., p. 5.

274 Ibid.

275 Ibid.

the program to women only or the program would be considered discriminatory.[276] ORWH overcame this problem by also accepting men. As a result, the program has served 35 women and 3 men.[277]

The director of ORWH sees the office's role as initiating new or pilot programs to address women's health concerns and facilitate the incorporation of women's health and career issues into institute and center sponsored initiatives. According to the director, a huge departmental effort has been underway for the past year that may lead to a departmentwide women's initiative. The director hopes that the new initiative would enhance the visibility of women's health efforts and programs throughout the Department.[278]

According to the director, the office has no direct involvement in the Secretary's initiatives on racial disparities in health.[279] Some of the ORWH staff collaborate with the HHS Office on Women's Health on particular activities within those initiatives concerning minority women. But minority issues are mainly the purview of the Office of Research on Minority Health.[280] The director of ORWH also stated that the office has not had any contact at all with HHS/OCR. OCR has not requested any of ORWH's reports. According to the director, her office had been unaware of the OCR pamphlet "Civil Rights Under Grants and Contracts"[281] until ORWH received the complete package of documents NIH submitted to the Commission, in which it was included.

Women's Health Programs and Initiatives

Since 1994, NIH has had approximately 100 interagency agreements on women's health initiatives. These agreements, which support initiatives funded by NIH, are between NIH's institutes and other Federal agencies, as well as between NIH and other HHS entities.[282] These initiatives include funding for research on different health care problems that affect women, such as breast cancer and pregnancy; outside activities such as conferences and workshops on women's issues; studies and reports on women's issues; and different programs and projects in the United States and abroad.[283]

In 1997 the Public Health Services' Office on Women's Health, the National Institutes of Health's Office of Research on Women's Health, and the Health Resources and Services Administration released a report in response to a congressional directive to assess women's health training in medical schools.[284] It is a comprehensive study on how women's health issues are taught in the basic and clinical sciences. The report includes the analytical results of two associations' surveys. It also presents the components of women's health curriculum and activities in medical schools, residency training, and professional programs.[285]

In 1998 the Office of Research on Women's Health and the Health Resources and Services Administration released a comprehensive study on how women's health and gender-related issues are taught in dental schools.[286] The report includes analytical results of a 1997 survey of U.S. and Canadian dental schools.

In 1998 the Office of Research on Women's Health released the *Women of Color Health Data Book* to address the barriers in health care services and health concerns of minority women. Such barriers include the need for cultural diversity among researchers, closer relationships between researchers and the communities being studied, and appreciation of differences in cultural beliefs of participants.[287] The data book, which is viewed as a resource book for policymakers and advocates in understanding the

[276] Ibid.

[277] Ibid.

[278] Ibid., p. 6.

[279] Ibid.

[280] Ibid.

[281] Ibid.

[282] *See* NIH, Response to Information Request, tab 15, "Inter-Agency Agreements Concerning Women's Health," FY 1994–1998.

[283] *See* ibid.

[284] HHS, Public Health Service, Health Resources and Services Administration, National Institutes of Health, *Women's Health in the Medical School Curriculum: Report of a Survey and Recommendations,* June 1997, p. vii.

[285] Ibid, p. 3.

[286] Ibid., Introduction letter.

[287] HHS, National Institutes of Health, Office of Research on Women's Health, *Women of Color Health Data Book: Adolescents to Seniors,* pp. iii–iv.

health status and issues concerning minority women, is available in English and Spanish.[288]

Extramural Associates Program

This program provides opportunities for women and minority institutions to participate in and contribute toward biomedical research. Under the program, NIH invites science administrators from academic institutions to participate in training and rotating work assignments at NIH and elsewhere. The program consists of coursework, assignments, and other experiences designed in consultation with a senior NIH scientist administrator who also serves as the participant's advisor. The candidate for participation is usually serving as the institution's administrator for biomedical or behavioral research at a historically black college or university, or any other minority or women's college or university.[289]

Research Supplements for Underrepresented Minority Students and Staff/Faculty

NIH supports many research supplement programs for underrepresented minority students and faculty:

- The high school program enables minority students to obtain a meaningful experience in various aspects of health-related research to stimulate their interest in careers in biomedical or behavioral science. Any minority high school student who is currently enrolled and in good standing at a participating high school may participate in the program.[290]
- The undergraduate program enables minority undergraduate students interested in biomedical or behavioral research to participate in a research project at a research institution during the summer months or during the school year. The student may be affiliated with the applicant institution or another institution.[291]
- The minority graduate research assistants program enables minority graduate students in biomedical and behavioral sciences to develop their research abilities. Any minority graduate student who is enrolled in a master's or a doctoral degree program in biomedical or behavioral sciences is eligible for consideration.[292]
- The postdoctoral training program provides research support for underrepresented minority individuals in the postdoctoral phase to participate in ongoing research projects to assist in their development to become independent biomedical or behavioral researchers. The minority postdoctoral candidate may be affiliated with the applicant institution or another institution.[293]
- The minority investigators program provides short- or long-term research support for minority faculty members to enhance their research skills for an independent research career. The participant may be affiliated with the applicant institution or another institution. The applicant must have a doctoral degree, be past the level of a research trainee, and be a member of the faculty with at least 1-year of postdoctoral experience.[294]

NIH also sponsors the Predoctoral Fellowship Awards for Minority Students and Students with Disabilities. These fellowships provide up to 5 years of support for research training leading to a doctorate or equivalent research degree, the combined M.D./Ph.D. degree, or other combined professional doctorate/research Ph.D. degrees in the biomedical or behavioral sciences. The Predoctoral Fellowship Program for Minority Students is intended to encourage minority students who are underrepresented in the biomedical and behavioral sciences to seek graduate degrees and, thus, further the goal of increasing the number of minority scientists in the biomedical and behavioral research fields.[295]

Under NIH's Minority Access to Research Careers (MARC) Honors Undergraduate Research

[288] HHS, National Institutes of Health, Office of Research on Women's Health, *Libro De Datos Sobre La Salud De Las Mujeres De Color: De La Adolescencia A La Tercera Edad,* pp. iii–iv.

[289] HHS, National Institutes of Health, Grants Information Office, Division of Research Grants, "NIH Minority Programs," undated, FY 1994–FY 1997, p. 3.

[290] Ibid., pp. 3–4.

[291] Ibid., p. 4.

[292] Ibid., p. 5.

[293] Ibid.

[294] Ibid., pp. 5–6.

[295] NIH, Response to Information Request, tab 8, "NIH Predoctoral Fellowship Awards for Minority Students and Students with Disabilities," p. 1.

Training Program, the goal is to increase the representation of minorities in the biomedical sciences at the undergraduate level. Under the MARC program, qualified minority institutions receive support to provide science courses and research training for honors students who are usually in their third and fourth year of college.[296] In 1995 the National Institute of General Medical Sciences, the NIH component responsible for the program, prepared a report to evaluate the outcomes of the MARC program. The report concluded that substantial percentages of former trainees have chosen careers with a research focus. The study suggests that MARC participants have pursued and obtained Ph.D.s, M.D.s, and other degrees at greater rates than minority biology and chemistry students who did not participate in the program.[297]

Although there is no current internal or external report on all minority programs, there is a proposed full-scale evaluation of the Research Centers in Minority Institutions program that will include data analyses, models, and recommendations for the program. A final report would be expected in FY 2000.[298]

Other NIH Minority Programs, Initiatives, and Studies

National Institute of Allergy and Infectious Disease

The National Institute of Allergy and Infectious Disease (NIAID) held workshops called Bridging the Career Gap for Underrepresented Minority Scientists in 1993, 1995, and 1997.[299] The workshop is a 2-day intensive program that targets minority researchers who are receiving research supplements and training awards at the time of the workshop. The workshop was designed to facilitate networking, grantsmanship, and academic collaboration among young minority scientists and members of the government, industry, and academic communities.[300] One of the primary goals of the workshop is to increase the number of minorities who receive research grants. Agenda items included career choices, funding opportunities, and keys to success.[301] In assessing the effects of the 1993 and 1995 workshops, most respondents thought the workshop was comprehensive and well organized and recommended that it be held again.[302] It was noted that although men and women were similar in their perceptions of the barriers that have influenced their careers, more women felt unprepared to compete for research grants.[303]

National Institute of Child Health and Human Development

In July 1997, the National Institute of Child Health and Human Development (NIAID) sponsored a 2-day conference titled Scientists, Tools and Research for the 21st Century.[304] The conference recognized the achievements of promising researchers and offered participants the opportunity to hear from graduates of the program, to interact with NICHD intramural and extramural staff, and to present their own work. Conference participants included individuals from Emory University School of Medicine, Texas Woman's University, and Morehouse University School of Medicine. As a result of the conference's success, NICHD scheduled a second conference for the summer of 1999. This second conference enabled NICHD to continue to monitor and showcase the success of its Minority Supplement Program.[305]

National Institute of Environmental Health Sciences

The National Institute of Environmental Health Services (NIEHS) has sponsored numerous programs and workshops targeting high school, college, and graduate/medical school students, high school teachers, and faculty from underrepresented minority and women's colleges

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[296] HHS, National Institutes of Health, National Institute of General Medical Science, "A Study of the Minority Access to Research Careers Honors Undergraduate Research Training Program," August 1995, p. ii.

[297] Ibid., p. vii.

[298] NIH, Response to Information Request, cover letter, p. 6.

[299] HHS, National Institutes of Health, National Institute of Allergy and Infectious Diseases, "Bridging the Career Gap for Underrepresented Minority Scientists Workshop Assessment," 1993 and 1995, p. 1.

[300] Ibid., p. v.

[301] Ibid., p. v.

[302] Ibid., p. 25.

[303] Ibid., p. 2.

[304] Duane Alexander, director, National Institute of Child Health and Human Development, National Institutes of Health, HHS, memorandum to John Ruffin, associate director for Research on Minority Health, National Institutes of Health, HHS, Jan. 20, 1999 (re: study of HHS by the USCCR).

[305] Ibid.

and universities.[306] For example, the Best program is a partnership between NIEHS and the Durham Public Schools in North Carolina to address science education concerns and needs particularly among disadvantaged and minority groups. The program is designed to heighten Durham Public School students' science involvement, specifically in the area of molecular biology, and to engage them in related supplementary activities that will enhance their probability of success in the sciences.[307]

Other programs include the Minority Worker Training Program, which was established to provide a series of national pilot programs to test a range of strategies to recruit and train young persons for environmental work. The program promotes partnerships or agreements with academic and other institutions, with a particular focus on historically black colleges and universities. Cooperative agreements with academic and other institutions have provided funding for seven programs to train minority inner-city youth.[308]

Another program is the North Carolina Transition Program in the Biomedical Sciences, which is funded by NIH and is a joint venture between the North Carolina community college system and the University of North Carolina system. The program is designed to increase the number of disadvantaged community college students who participate in advanced education and training leading to a baccalaureate degree in biomedical sciences.[309]

In response to Executive Order 12876, the NIEHS has developed a pilot program, the Advanced Research Cooperation in Environmental Health (ARCH), which focuses on establishing research partnerships between investigators at research intensive universities with significant environmental health sciences research and historically black colleges. This effort at the HBCUs is based, in part, on their success in producing graduates who have pursued advanced degrees in biomedical sciences. The goal of the program is to establish a group of investigators at HBCUs who can successfully compete for NIH/NIEHS research project grant support, typically RO1 grants.[310] The RO1 grant provides up to $1 million per year for training, and administrative and research support for a period of up to 5 years.[311] To achieve this goal, NIEHS plans to establish collaborative thematic program projects between HBCUs and research intensive universities. It is expected that the HBCU scientists will compete for other types of NIH/NIEHS grants during the period of this pilot program.[312]

Other NIEHS efforts include: (1) developing innovative approaches for increasing the participation of minority institutions in the training of environmental scientists; this has been fostered at the University of Vermont in conjunction with Delaware State University, at the University of Texas Health Science Center with Texas Southern University, and at Vanderbilt University with Meharry Medical College; and (2) a short-term training program, National Research Service Award, for undergraduate minorities to develop their interests and skills in research. The goal of this program is to attract talented students to Ph.D. programs in environmental health sciences. In FY 1997 more than 60 students were supported at 14 training grant sites.

National Institute of General Medical Sciences

Between fiscal years 1994 and 1998, the National Institute of General Medical Sciences (NIGMS) sponsored several technical assistance workshops for minority principal investigator applicants.[313] For instance, in April 1998, NIGMS' Minority Access to Research Careers Branch provided support through the Federation of American Societies for Experimental Biology to hold a seminar on NIH and NIH Grantsmanship at the Experimental Biology Annual Meeting.[314] Approximately 210 individuals attended

[306] John Schelp, National Institutes of Health, National Institute of Environmental Health Sciences, memorandum to Jean Flagg-Newton, special assistant to director of ORMH, Jan. 21, 1999 (re: study of HHS by the USCCR).

[307] Ibid., p. 2.

[308] Ibid., p. 3.

[309] Ibid., p. 4.

[310] Ibid., p. 6.

[311] Ibid.

[312] Ibid.

[313] Marvin Cassman, director, National Institute of General Medical Sciences, National Institutes of Health, HHS, memorandum to John Ruffin, associate director for Research on Minority Health, National Institutes of Health, HHS, Jan. 19, 1999 (re: study of HHS by the USCCR), attachment. *See* the discussion of the MARC program in the section titled "Research Supplements, Fellowships and Honors for Underrepresented Minority Students and Staff/Faculty" above.

[314] Ibid.

the seminar.[315] In June 1998, the branch held a seminar on the art of grant writing at the Federation of American Societies for Experimental Biology headquarters.[316]

During fiscal years 1997 and 1998, NIGMS' Minority Opportunities in Research Division conducted 15 and 23 "outreach visits," respectively, to minority institutions. NIGMS reported that seven of the institutions visited in 1997 submitted applications for the Minority Access Research Careers or MBRS programs; and five institutions (all of them HBCUs) received grant awards.[317]

National Institutes of Mental Health

Since 1994, National Institutes of Mental Health (NIMH) has held several technical workshops and meetings on to minorities and women in mental health research and has contributed to conferences on the subject.[318] Between 1994 and 1998, NIMH funded a 1-day special workshop geared to the 30 to 40 Minority Fellowship Program participants attending the annual meeting of the Council on Social Work Education.[319] The workshops cover specific substantive areas of mental health research, opportunities for postdoctoral training, and dissertation and other research support.[320] For the past 5 years, NIMH's Division of Basic and Clinical Neuroscience Research has organized a women neuroscientists meeting at the Society for Neuroscience's annual meeting.[321] Approximately 30 to 40 female neuroscientists have gathered to hear NIMH staff discuss the institute's program initiatives, programmatic and administrative issues related to the NIH grant application process, and issues on training and career development for women in the neuroscience.[322]

In 1995 NIMH staff chaired a panel and provided technical assistance on grant writing at a meeting held for HBCU faculty and organized by faculty from Drew Medical University.[323] The meeting was part of the Second Annual Conference on Psychopathology, Psychopharmacology, Substance Abuse, and Ethnicity.[324] Also in 1995, before the White House Conference on Aging, NIMH staff presented keynote addresses at three "mini conferences" sponsored by various HBCUs—one by Paine College (in Augusta, Georgia); another by a consortium of three HBCUs in Atlanta, Georgia (including Morehouse Medical School); and a third by the Association of Gerontology and Human Development Programs in HBCUs.[325]

NIMH staff have also provided technical assistance on grant writing, study design, and clinical research priorities to faculty at HBCUs, in order to plan a joint research project between Lincoln Cooperative Extension Service and the University of Missouri—Kansas City.[326] Similarly, NIMH staff have lectured and participated in the planning and agenda development activities of the Washington, D.C., Geriatric Education Center, a consortium based at Howard University.[327] In addition, NIMH's Office on AIDS held a technical assistance workshop on grant writing for six HBCUs.[328]

National Institute on Drug Abuse

Between 1994 and1998, National Institute on Drug Abuse (NIDA) sponsored or cosponsored several technical assistance meetings that targeted underrepresented minority scholars to encourage them to pursue careers in substance abuse research.[329] For instance, throughout each year, NIDA held its 2-day Special Populations Research Development Seminars, which provided underrepresented minorities and women with the essential tools and mentoring to design

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[315] Ibid.

[316] Ibid.

[317] Ibid.

[318] Sherman L. Ragland, deputy associate director for Special Populations, National Institute of Mental Health, HHS, memorandum to associate director for Research on Minority Health, HHS, through Jean L. Flagg-Newton, National Institutes of Health, HHS, Jan. 21, 1999 (re: study of HHS by the USCCR), attachment.

[319] Ibid., p. 1.

[320] Ibid.

[321] Ibid.

[322] Ibid.

[323] Ibid.

[324] Ibid.

[325] Ibid.

[326] Ibid.

[327] Ibid.

[328] Ibid., p. 2.

[329] Alan I. Leshner, director, National Institute on Drug Abuse, National Institutes of Health, HHS, NIDA, memorandum to John Ruffin, associate director for Research on Minority Health, National Institutes of Health, HHS, Jan. 29, 1999 (re: study of HHS by the USCCR).

competitive research proposals in the drug abuse sciences.[330] Some of the themes of various seminar series workshops from 1994 to 1998 included women in clinical and behavioral research, minorities in drug abuse, minority supplements fellows training program, and violence research among Hispanic populations.[331] Each of these meetings focused on research design and methodology, scientific writing, the NIH peer review process, and strategies to prepare and submit grant applications.[332] To date, NIDA has not assessed or evaluated its Special Populations Research Development Seminar Series but plans to do so in the future.[333]

NIDA's Drug Abuse Research Technical Assistance Project (DARTAP) is another major technical assistance initiative geared to increasing the participation of minorities engaged in drug abuse research.[334] The Drug Abuse Research Technical Assistance Program was funded from 1994 to 1998 to provide technical assistance to faculty/staff (all of whom had terminal degrees) from 12 of the Nation's 88 4-year HBCUs.[335] Participants were selected based on prior research experience, and represented HBCUs such as Clark Atlanta University, Florida A&M University, Jackson State University, South Carolina State University, and University of Maryland—Eastern Shore.[336] Technical assistance was provided through several workshops; telephone conference calls; and information on NIDA programs, activities, and substance abuse funding sources.[337] NIDA grantees also served as mentors to DARTAP participants, to assist them in developing research proposals.[338]

During the Drug Abuse Research Technical Assistance Project program's third and fourth years, numerous participants received NIDA grants, as well as other government, and nongovernmental research grants.[339] NIDA's assessment of the Drug Abuse Research Technical Assistance Project program revealed that faculty/staff brought a "fresh perspective" to the drug abuse field; were well-connected to their communities; and were concerned about minority rural youth's extent of drug use, youth's perception of drug use risks, drug abuse prevention among women, and other areas.[340] For future similar technical assistance programs that target minority institutions, NIDA recommends that seed money be provided to faculty/staff so that they can obtain release time from their institutions to focus solely on grant applications; that Federal minority initiatives that tap the same faculty at HBCUs make efforts to coordinate with one another, to enable faculty to "focus on issues that affect the surrounding community"; and that special consideration be given to NIDA grant applications from HBCU faculty/staff so that they "become acclimated to drug abuse research."[341]

Occasionally, NIDA has sponsored meetings that specifically address drug abuse research on minority populations.[342] Between 1994 and1998, some of these meeting were titled: Drug Addiction Research and Health of Women, Drug Abuse Research with Minority Populations: Methodological and Theoretical Issues and Concerns, The Development and Retention of African American Investigators in Research Careers, and Research Training Seminars for Hispanic Researchers.[343]

National Institute on Alcohol Abuse and Alcoholism

Although the National Institute on Alcohol Abuse and Alcoholism (NIAAA) has not done any evaluations to track the progress of minorities' and women's representation among alcohol abuse researchers, the institute has held several technical workshops and implemented several other initiatives to help current minority and women investigators and to encourage other minorities and women to participate in the realm of alcohol abuse research.[344] Some of the workshops

330 Ibid., p. 1.

331 Ibid., p. 2.

332 Ibid., p. 1.

333 Ibid., p. 2.

334 Ibid.

335 Ibid.

336 Ibid., attachment, figure I, "Institutions Participating in TA Project September 1994–September 1998."

337 Ibid., pp. 2–3.

338 Ibid., p. 3.

339 Ibid.

340 Ibid., attachment, "Assessment of *DARTAP* Project," pp. 1–2.

341 Ibid., attachment, "Assessment of *DARTAP* Project," pp. 5–6.

342 Ibid., pp. 3–4.

343 Ibid.

344 Enoch Gordis, director, National Institute on Alcohol Abuse and Alcoholism, HHS, memorandum to John Ruffin,

have provided "traditional technical assistance," and others have focused on research on alcohol concerns related to women and minorities and fostered the collaboration of minority institution investigators and experienced researchers on alcohol research projects.[345] NIAAA has also developed one-on-one technical assistance programs and has designed a new program for "distance learning" technical assistance.[346]

Traditional Technical Assistance Workshops. In both October 1994 and 1995, NIAAA held workshops in Washington, D.C., to encourage potential grantees (of whom "a sizable number were minority investigators") to apply for grants in the areas of alcohol abuse and alcoholism.[347] At the 1995 workshop, topics focused on: (a) research methodology issues, such as framing research questions, statistical sampling, constructing models, analyzing results, and cross-cultural research concerns; (b) requirements in preparing grant applications and accompanying budgets; and (c) results from research studies (one of which was on women and minorities) conducted by NIAAA staff.[348] NIAAA reported that 7 of the 32 participants were members of minority groups.[349]

A May 1996 technical assistance research workshop in Washington, D.C., was held exclusively for 21 potential minority investigators.[350] Topics addressed were similar to those of the October 1994 and 1995 workshops.[351] In addition, NIAAA staff led small group discussions to guide the development of research applications.[352] Special attention was given to defining research objectives and discussing research methodology.[353]

Alcohol Abuse Research Affecting Women and Minorities. In November 1998, NIAAA held a 2-day workshop to assess the status of women and alcohol problems and to develop an agenda for revised priorities in health services research.[354] Presentations covered issues such as the effect of welfare reform on alcohol treatment for women, pregnant medicaid recipients who abuse alcohol, barriers to women in rural areas when seeking alcohol services, and special concerns of older women who have alcohol abuse problems.[355] Part of developing an agenda on health services research included NIAAA's appointing a panel of experts to evaluate literature on issues such as gender disparities in the types and course of treatment and barriers confronted by women in obtaining care (e.g., lack of child care, limited financial resources), and scheduling a roundtable discussion for later in 1999 to identify the "elements within women's lives" that should be addressed in research and in treatment models for women with alcohol problems.[356]

NIAAA's Efforts to Collaborate with Minority Institutions. In 1997 NIAAA held two workshops to begin a network of minority investigators in the areas of alcohol prevention/intervention research, epidemiology of alcohol-related problems, cultural issues, and AIDS.[357] The January workshop in Chapel Hill, North Carolina, covered environmental issues, alcohol-related social movements in African American communities, and strategies to develop and implement community-based evaluation and research.[358] The April workshop in Los Angeles, California, addressed the epidemiology of alcohol dependence, alcohol and violence, screening for alcohol abuse problems, and HIV/AIDS and alcohol.[359]

NIAAA's Efforts to Provide Technical Assistance. For the past 3 years, NIAAA has made a concerted effort to assist minority researchers in developing competitive grant applications or revising previous unsuccessful applications.[360] One-on-one technical assistance has also been provided to nonminority investigators interested in researching the implications of alcohol abuse problems among minority individuals. In some cases, NIAAA funded its applicants' air trans-

associate director for Research on Minority Health, National Institutes of Health, HHS, Jan. 22, 1999 (re: study of HHS by the USCCR), attachment.

345 Ibid., attachment, p. 1.

346 Ibid.

347 Ibid., attachment, p. 1.

348 Ibid.

349 Ibid.

350 Ibid.

351 Ibid.

352 Ibid.

353 Ibid.

354 Ibid., attachment, p. 2.

355 Ibid., attachment, pp. 1–2.

356 Ibid., attachment, p. 2.

357 Ibid., attachment, pp. 1–2.

358 Ibid.

359 Ibid., attachment, p. 2.

360 Ibid.

portation for them to meet their NIAAA mentors in person.[361]

NIAAA is also establishing the Alcohol Research Mentoring Research System, which is a "learning program" to assist potential investigators not affiliated with "mainstream alcohol research centers."[362] The program will be directed by an 8A contractor; and assistance will be provided via e-mail and telephone.[363] NIAAA has distributed information about the mentoring system to alcohol research organizations explicitly to solicit ethnic minority applicants.[364]

National Heart, Lung, and Blood Institute

Between 1994 and 1998, National Heart, Lung, and Blood Institute (NHLBI) assessed two of its minority training programs, Short-term Training for Minority Students Program (STMSP) and Research Supplements for Underrepresented Minorities Program, to make program modifications or develop new programs based on the outcome of the assessments.[365] The short-term program is actually a 5-year opportunity that gives institutions broad latitude in the development and implementation of programs geared to increasing the number of minority students pursuing careers in the biomedical and behavioral sciences.[366] The evaluation revealed that the STMSP is one of several programs that has stimulated many universities and foundations to make efforts to increase interest and participation of minority individuals in the biomedical and behavioral sciences.[367] However, the NHLBI acknowledges that continuing to reduce the shortage of qualified minority researchers and increasing the overall number of minorities pursuing biomedical and behavioral sciences require the implementation and replication of effective training programs.[368] Overall, faculty and staff at participating institutions believe that enhancing trainees' knowledge of typical research duties is the primary strength of the STMSP, followed closely by outcomes such as improving the trainees' research skills and understanding of the educational requirements for science research careers, and informing trainees of the range of positions in the biomedical field.[369]

In FY 1998, NHLBI analyzed its minority supplements program.[370] The mission of NHLBI's Research Supplements for Underrepresented Minorities Program is to "increase the number of highly trained underrepresented minority individuals whose basic or clinical research interests are grounded in the advanced methods and experimental approaches needed to solve problems related to cardiovascular, pulmonary, and blood health and diseases; transfusion medicine; and sleep disorders."[371] The funds are disseminated to currently funded grantees so that they can recruit and train underrepresented minority high school, undergraduate, and graduate students; postdoctoral fellows; and faculty and research staff.[372]

Between 1995 and 1996, the institute held two technical assistance workshops to assist prospective minority grantees in preparing applications for research funds.[373] At the June 1995 workshop, more than 100 individuals who had "active or recent minority supplements" as investigators, postdoctoral fellows, or graduate students attended.[374] The workshop held sessions on planning a research career, the role of mentors in research careers, the likelihood of NHLBI grant support, a critique of NHLBI minority supplements program, and non-NIH sources of research funds.[375]

NHLBI's September 1996 workshop was cosponsored with NIH's Office of Research on Minority Health.[376] Panel topics included targeting and improving diversity in biomedical research, developing partnership guidelines, assessing

361 Ibid.

362 Ibid.

363 Ibid.

364 Ibid.

365 Claude Lenfant, director, National Heart, Lung, and Blood Institute, HHS, memorandum to John Ruffin, associate director for Research on Minority Health, National Institutes of Health, HHS, Jan. 19, 1999 (re: study of the HHS by the USCCR).

366 Ibid., p. 1.

367 Ibid.

368 Ibid.

369 Ibid.

370 Ibid.

371 Ibid.

372 Ibid.

373 Ibid., p. 2.

374 Ibid.

375 Ibid.

376 Ibid.

current collaborative partnership programs, and determining how existing NIH programs can enhance partnership development.[377] Handouts covered subjects such as NHLBI-supported National Research Service Award Training programs; other NHLBI grant and career training programs; sources of non-Federal support for heart, lung, and blood research; and a directory of minority-serving institutions.[378]

National Institute of Arthritis and Musculoskeletal and Skin Diseases

On April 16, 1996, in conjunction with the National Institute of Arthritis and Musculoskeletal and Skin Diseases' (NIAMS) 10th anniversary, the institute held a workshop on the NIH main campus for NIAMS-supported underrepresented minority scientists.[379] Topics covered included career challenges faced by minority scientists, mentoring and networking in career development, various grant opportunities that are appropriate during different career stages, and private sources of research funds.[380] The majority of the conference's 33 participants were black, Hispanic, Native American, and Asian American and Pacific Islander graduate students, postdoctoral fellows, and investigators.[381]

National Institute of Diabetes and Digestive and Kidney Diseases

Since 1994, the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) has conducted and assessed a few research programs geared to minority and women researchers and teachers.[382] For instance, between October and November 1994, NIDDK sponsored a Special Topics in Biotechnology course for District of Columbia public school teachers.[383] Some of the scientific goals of the workshop included learning the fundamental concepts of immunology, about the production and characterization of antibodies, and how vaccines are developed, tested, and used.[384]

NIDDK has also held several technical assistance workshops at professional associations and meetings and research forums at universities.[385] For instance, in March 1997, NIDDK sponsored the National Hispanic Medical Association's first annual conference.[386] Conference presentations included the changing health care environment facing Latino communities, corporatization of health care, and the medical management of Latino patients.[387] In July 1997, at a 3-day conference of the Society for the Advancement of Chicanos and Native Americans in Science, a representative of NIDDK gave the institute's perspective of peer review issues affecting applicants and reviewers.[388]

In August 1998, NIDDK participated in the NIH/National Medical Association (NMA) Annual Symposium of the NMA Annual Convention and Scientific Assembly.[389] The NIH-NMA partnership addresses health issues that affect minority populations and provides a platform to address issues related to the President's initiative to reduce the disparities in minority health status.[390] The 1998 symposium addressed three areas: the potential benefits of "practiced-based research" for black physicians and patients,

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[377] Ibid.

[378] Ibid.

[379] Stephen I. Katz, director, National Institute of Arthritis and Musculoskeletal and Skin Diseases, HHS, memorandum to John Ruffin, associate director for Research on Minority Health, National Institutes of Health, HHS, Jan. 21, 1999 (re: study of HHS by the USCCR), attachment.

[380] Ibid., p. 1.

[381] Ibid., attachment, pp. 14–20.

[382] Phillip Gorden, director, National Institute of Diabetes and Digestive and Kidney Diseases, National Institutes of Health, HHS, memorandum to John Ruffin, associate director for Research on Minority Health, National Institutes of Health, HHS, Jan. 21, 1999 (re: study of HHS by the USCCR, attachments) (hereafter cited as NIDDK memo).

[383] HHS, National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases; District of Columbia Public Schools; and Foundation for Advance Education in the Sciences, Inc., *Special Topics in Biotechnology Course Report*, Oct. 22–Nov. 17, 1994, p. 1.

[384] Ibid., p. 3.

[385] Ibid., attachment, "NIDDK Federal Assistance Programs."

[386] Elena Rios, National Hispanic Medical Association, letter to Rose Pruitt, National Institute of Diabetes and Digestive and Kidney Diseases, National Institutes of Health, HHS, June 1, 1997 (re: appreciation of NIDDK's sponsorship of the National Hispanic Medical Association's first annual conference), attachment.

[387] Ibid., attachment, p. 4.

[388] NIDDK memo, attachment, "Society for the Advancement of Chicanos and Native Americans in Science, July 11, 1997, Conference Agenda," p. 3.

[389] NIDDK memo, attachment, "NIH/NMA Symposium of the National Medical Association Annual Convention and Scientific Assembly."

[390] Ibid., p. 1.

strategies to track the emergence of hepatitis C among the black community, and opportunities for NIH funds in biomedical research.[391] In November 1998, NIDDK participated in Temple University's Minority Trainee Research Forum.[392] Between 1994 and 1998, NIDDK also held technical assistance workshops at annual meetings of the following organizations: American Indian Science and Engineering Society, Association of Minority Health Professions Schools, Hispanic Association of Colleges and Universities, and the National Council of La Raza.[393]

National Cancer Institute

The National Cancer Institute's (NCI) Office of Special Populations Research, located in the Office of the Director, is responsible for coordinating cancer research related to minorities, women, and other "special populations."[394] The Office of Special Populations Research and other NCI divisions and offices have sponsored technical assistance meetings and workshops and training programs geared to engaging minorities and women in cancer research.[395] For instance, the Comprehensive Minority Biomedical Program (CMBP) has eight types of training awards and fellowships (predoctoral to clinical investigator) to broaden participation in cancer-related research and training activities by minorities, people with disabilities, and individuals aiming to reenter the cancer research field.[396] The program also attempts to assist cancer treatment programs in reaching minorities and other historically underserved populations.[397]

In July 1998, as part of the CMBP, the Office of Special Populations Research, in conjunction with the Division of Cancer Prevention, Early Detection Branch, sponsored a 2-day workshop titled Participation of Women and Minorities in Clinical Cancer Research.[398] Regional clinical trials and special minority issues, as well as recommendations to the NCI, were addressed.[399] The work session on regional clinical trials covered issues, such as regional and local barriers faced by minority communities (e.g., economic, cultural, lifespan), strategies to overcome the barriers, cultural attitudes related to informed consent, and additional research needs.[400]

In addition, NCI's Division of Cancer Prevention and Control designed and supports the Minority-based Community Clinical Oncology Program.[401] This initiative aims to: (a) provide support to expand clinical research in minority community settings; (b) implement the most recent cancer prevention, control, treatment, and research techniques in minority communities; (c) encourage primary health care providers and other specialists to conduct cancer prevention and control studies; and (d) establish an operational base for extending cancer prevention and control, to reduce cancer incidence, morbidity, and mortality in minority populations.[402]

The Office of Special Populations Research sponsors the National Black Leadership Initiative on Cancer, which aims to: (a) convene community leaders in building new and maintaining existing community cancer control coalitions; (b) address barriers that limit blacks' access to quality cancer prevention, control, and treatment services; (c) improve minorities' knowledge of and attitude toward prevention and early detection of cancer; and ultimately (d) reduce cancer incidence and mortality rates and increase the survival rates among black individuals.[403]

In December 1997, NCI held an Asian American/Pacific Islander Workshop to address and assess cancer concerns and needs of the AAPI community.[404] Strategies and models for cancer

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391 Ibid.

392 Moses L. Williams, director of Admissions, Temple University School of Medicine, letter to Rose E. Pruitt, National Institute of Diabetes and Digestive and Kidney Diseases, National Institutes of Health, HHS, Nov. 12, 1998 (re: Minority Trainee Research Forum).

393 NIDDK memo, attachment, "NIDDK Federal Assistance Programs."

394 Barbara Bonaparte, program specialist, Office of Special Populations Research, National Cancer Institute, HHS, memorandum to John Ruffin, associate director for Research on Minority Health, National Institutes of Health, HHS, Feb. 1, 1999 (re: study of HHS by the USCCR), attachments (hereafter cited as NCI memo).

395 Ibid.

396 Ibid., pp. 2–3.

397 Ibid., p. 2.

398 Ibid., attachment 1, "Participation of Women and Minorities in Clinical Cancer Research Workshop," July 13–14, 1998, Workshop Agenda.

399 Ibid., pp. 1–2.

400 Ibid., agenda for July 14, 1998, Work Session #2, p. 2.

401 NCI memo, p. 4.

402 Ibid.

403 Ibid, attachment 2, "Minority Based CCOPS Workshop: Principal Investigators," Sept. 14, 1998, Workshop Agenda.

404 Ibid., p. 5.

prevention and control as well as cancer research were presented.[405] On October 9, 1998, NCI convened physicians, scientists, and community health advocates to hold its first National Clinical Trials and Asian American Women Summit. The aim was to: (a) determine the extent of and increase Asian American women's participation in clinical trials; (b) address factors that affect clinical trial participation (e.g., cultural views, economic barriers, and ethnic responses to medications and treatments); and (c) develop recommendations to increase the involvement of Asian American women in all aspects of clinical trial research and implementation.[406]

National Institute on Deafness and Other Communication Disorders

In 1994 the National Institute on Deafness and Other Communication Disorders (NIDCD) established a partnership with NIH's Office of Research on Minority Health to address the underrepresentation of minorities, women, and hearing-impaired persons in the sciences, and to provide training opportunities to students, faculty, and administrators from institutions historically underrepresented in research.[407] Between 1994 and 1997, 65 individuals participated in almost 100 training opportunities that lasted from a few weeks to more than a year. Most of the opportunities focused on basic, clinical, and epidemiological research; but some focused on policy and administrative issues and scientific writing.[408]

NIDCD claims that the partnership program is unique because of the flexible timing options, participants' eligibility to receive multiple training, and customized experiences to fit participants' needs and goals. Candidates have been selected from a pool of several HBCUs in the Atlanta, Georgia, area and four other universities, including Gallaudet University, a 4-year liberal arts college for hearing-impaired students, and the University of Puerto Rico, which serves large concentrations of underrepresented individuals.[409]

In September 1997, NIDCD held a 2-day meeting to explain the justification for and the goals and outcomes of the partnership program.[410] The second day of the meeting focused on addressing program limitations and recommendations for improvement.[411] Some of the concerns raised were about NIDCD's small size, which limits the number of trainees to be accommodated at any one time; certain underrepresented populations not being included in the program; and the lack of sufficient mentoring skills in some supervisors.[412] Recommendations focused on the need for the partnership program to better target Native Americans, hearing-impaired individuals, and Chicano and Cuban groups, and to expand types of training opportunities to include neuroscience, physiology, biomedical engineering, and applied math.[413]

National Institute of Dental and Craniofacial Research

The National Institute of Dental and Craniofacial Research's (NIDCR) Division of Extramural Research has held several technical assistance workshops to educate faculty members interested in the NIH research grants process about the need for more minority investigators in oral health research.[414] For instance, in April 1996, NIDCR's Division of Extramural Research, in conjunction with the Regional Research Centers for Minority Oral Health, held a workshop, to address funding opportunities for new investigators, strategic approaches to completing

[405] Ibid., attachment 5, "NCI Meeting on Asian American/Pacific Islanders (A/PI) Cancer Concerns," Dec. 4–5, 1997, Workshop Agenda.

[406] Ibid., p. 5, and attachment 4, "The National Clinical Trials and Asian American Women Summit," Oct. 9, 1998, Agenda.

[407] David Kerr, National Institute on Deafness and Other Communication Disorders, HHS, memorandum to associate director for Research on Minority Health, National Institutes of Health, HHS, Jan. 13, 1999 (re: study of HHS by the USCCR), attachment. Future, Mar. 13, 1998, executive summary, p. 1.

[408] Ibid., attachment, p. 1.

[409] Ibid., attachment, pp. 1, 10.

[410] Ibid., attachment, p. 3.

[411] Ibid., attachment, p. 4.

[412] Ibid., attachment, p. 15.

[413] Ibid., attachment, p. 16.

[414] Lorrayne W. Jackson, diversity program specialist, Division of Extramural Reassert, National Institute of Dental Research, HHS, memorandum to Jean L. Flagg-Newton, National Institutes of Health, HHS, January 1999 (re: study of HHS by the USCCR), attachment (hereafter cited as NIDCR, response to information request).

grant applications, and sources of NIDCR's research funds.[415]

In January 1998, the institute's National Advisory Dental Research Council held a 2-day meeting to address issues such as: (a) the "explosion" of technical/scientific and substance information and statistical data available to the public and dental researchers; (b) the allocation of funds to NIDCR's four Oral Health Research Clinical Care Centers; and (c) the Surgeon General's report on oral health.[416] The council mentioned that the dearth of student training opportunities in clinical investigations, the lure of more lucrative careers, and concerns about how repaying loans hinder the growth of the Nation's "new generation of scientists," and also deter minorities and women from entering dental and medical careers.[417]

In July 1998, the NIDCR Division of Extramural Research sponsored a grant-writing workshop specifically for faculty recipients of the NIDCR's Research Supplements for Underrepresented Minorities program and members of the Hispanic Dental Association.[418] At a 1-day October 1998 conference, 36 NIDCR grantees presented their research findings, many of which focused on minority populations.[419]

National Institute on Aging

In 1991 the National Institute on Aging (NIA) initiated a Summer Institute in Research on Minority Aging to focus on research issues relevant to minority populations and recruit minority participants.[420] In 1994 this institute merged with a multidisciplinary summer institute on aging. The expanded summer institute's curriculum includes issues relevant to minority aging research and the recruitment and retention of minority subjects in clinical trials.[421] Concerted efforts are made so that adequate numbers of minority scientists participate in the institutes.[422]

Overall, the Summer Institute on Aging Research aims to: (a) recruit "emerging scientists" into aging research; (b) discuss innovative teaching methodologies and identify scientific questions relevant to aging research; (c) stimulate multidisciplinary research and a team approach to resolving complex questions in aging research; and (d) foster the independence of emerging scientists by providing information relevant to NIH funding.[423] According to the director of the University of Minnesota School of Public Health's Institute for Health Services Research, the NIA Summer Institute provides an impetus for minority scientists, who have numerous career options, to enter into aging research.[424] In 1997, 20 percent of the institute's participants were racial/ethnic minorities.[425]

Between 1994 and 1998, NIA partnered with NIH's Office of Research on Minority Health to hold technical assistance workshops.[426] For instance, in November of 1994 and 1995, NIA held workshops specifically for minority investigators. The 1998 workshop addressed the programs of NIH's Office of Research on Minority Health.[427]

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415 Ibid., attachment, "Introduction to Grantsmanship Workshop," Apr. 11, 1996, Meeting Agenda.

416 HHS, National Institutes of Health, National Institute of Dental and Craniofacial Research, "Minutes of the National Advisory Dental Research Council," Jan. 20–21, 1998, pp. 1–6, accessed at <http://www.nidcr.nih.gov/discover/nadrc/nadrc198.htm>.

417 Ibid., p. 7. The president of the Dana Farber Cancer Center claimed that financial assistance is needed to support dental students, whose indebtedness on completing their professional training exceeds that of medical students. Ibid.

418 NIDCR, response to information request.

419 Ibid, attachment; HHS, National Institutes of Health, National Institute of Dental Research and Regional Research Centers on Minority Oral Health, Oct. 19, 1998, Conference Agenda.

420 "The Brookdale Foundation/National Institute on Aging Summer Institute on Aging Research, Report to the Brookdale Foundation," undated, p. 3 (hereafter cited as NIA memo). *See* J. Taylor Harden, assistant to the director for Special Populations, National Institute on Aging, HHS, memorandum to John Ruffin, associate director for Research on Minority Health, National Institutes of Health, HHS, Jan. 20, 1999, (re: study of HHS by the USCCR).

421 NIA memo, p. 3.

422 Ibid.

423 Ibid., p. 5

424 Rosalie Kane, director, Institute for Health Services Research, School of Public Health, University of Minnesota, memorandum to Brookdale Foundation Board of Directors, Nov. 5, 1997 (re: Brookdale/NIA Summer Institute), p. 1 (hereafter cited as Kane, Brookdale/NIA Summer Institute Memo).

425 Ibid., p. 1.

426 NIA memo.

427 HHS, National Institutes of Health, National Institute on Aging, "Technical Assistance Workshop for Minority Investigators," Nov. 1–2, 1995, Workshop Agenda.

National Institute of Nursing Research

The National Institute of Nursing Research (NINR) has sponsored several technical assistance workshops, and has developed, supported, and collaborated in several projects geared to furthering and publicizing research talents in women and minorities.[428] For instance, in both 1994 and 1998, NINR participated in national conferences of the Society for Advancement of Chicanos and Native Americans in Science.[429] Overall goals of the 1998 conference were to: (a) establish nationwide networks among students, educators, and professionals who are actively engaged in increasing the representation of minorities in science and health teaching and research; (b) mentor undergraduate and graduate students through workshops, summer programs, and other internships; (c) hold symposia to inform participants on the most recent research endeavors in science and health; and (d) provide a forum for Nobel laureates and other notable scientists and health professionals to share their research and career experiences.[430]

During the 1998 conference, NINR supported several technical workshops, including workshops on writing applications for graduate school and for research grants.[431] The objectives of these workshops were to enable undergraduate students to assess their options and make informed decisions about graduate and medical school and to develop strategies to help balance the demands of a medical/scientific career with family and personal responsibilities. A third objective was for all conference participants to understand the current trends in science and mathematics research and education.[432]

In conjunction with NIH's National Institute on Aging and the Office of Research on Minority Health, NINR supported a technical assistance workshop at a meeting of the Gerontological Society of America in 1997.[433] NINR specifically supported the presentations by a panel of leaders from several organizations, such as the National Association of Asian American and Pacific Islander Nurses, National Association of Hispanic Nurses, and National Black Nurses Association, that focused on minority health concerns and strategies to recruit minorities into nursing.[434]

During FY 1998, results from a major NINR research effort, Extending Advances in Cardiovascular Risk-Factor Management to Special Populations, included black males' reduced risk of cardiovascular disease.[435] NINR has also sponsored the research efforts of minority investigators to study issues such as the health status of elderly African American women and African American elderly and long-term care facilities.[436] NINR staff have also obtained external funds to conduct their own research on health issues concerning women and minorities, such as the effect of breast cancer on elderly black women, culturally sensitive treatment of HIV in Mexican Americans, and determinants of recovery from hip fracture.[437] The director of NINR informed the Commission that the Nursing Center engages in other activities related to minority investigator development and minority health care research through its technical assistance, publications and other dissemination activities, and outreach endeavors.[438]

National Center for Research Resources

Since 1994, the National Center for Research Resources (NCRR) has not completed any evaluations or reports on federally assisted programs aimed at women or minorities.[439] However, NCRR is in the process of evaluating its Research Centers in Minority Institutions Program and the Research Infrastructure in Minority Institutions Program.[440] In October 1998, NCRR collaborated with NIH's National Institute of Neurological Disorders and Stroke and

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428 Patricia Grady, National Institute of Nursing Research, National Institutes of Health, HHS, memorandum to associate director for Research on Minority Health, National Institutes of Health, HHS (re: study of HHS by the USCCR), attachment.

429 Ibid., p. 1.

430 Ibid., attachment.

431 Ibid.

432 Ibid., attachment.

433 Ibid., p. 1.

434 Ibid.; attachment, p. 2.

435 Ibid., pp. 1–2.

436 Ibid., p. 2.

437 Ibid.

438 Ibid.

439 Judith L. Vaitukaitis, director, National Center for Research Resources, National Institutes of Health, HHS, memorandum to John Ruffin, associate director for Research on Minority Health, National Institutes of Health, HHS, Jan. 25,1999 (re: study of HHS by the USCCR), attachment.

440 Ibid.

the Office of Research on Minority Health, to sponsor a 2-day workshop on specialized neuroscience programs at minority institutions.[441]

NCRR's Extramural Research Facilities Construction (ERFC) program is targeted to Centers of Excellence, which serve minority populations. Members of the Centers for Excellence community attended a December 1998 workshop that provided information on grantsmanship for the ERFC program.[442]

Warren G. Magnuson Clinical Center

NIH's Warren G. Magnuson Clinical Center is engaged in meeting Federal goals for improving health care research for women and minorities. While the clinical center is not mandated to provide research grants, the clinical research hospital of NIH sponsors programs specifically designed to train culturally competent health care practitioners and researchers, as well as to actively recruit women and minorities into clinical research trials.[443] For example, the clinical center was instrumental in establishing two programs for training clinical researchers. The Introduction to Principles and Practices of Clinical Research and the Clinical Center/Duke University collaborative course titled Training Program in Clinical Research both include substantive curricula on the inclusion of women and minorities in research trials.[444]

In 1996 the clinical center recognized the need to recruit patients for clinical protocols. To meet this goal, the Patient Recruitment and Public Liaison Office (PRPL) was established. PRPL provides a variety of outreach and recruitment activities funded in part through a grant from the Office on Research for Minority Health. The PRPL recruits for current institutes' protocols to ensure diversity in patient enrollment. Recruitment for clinical research studies on diseases that are prevalent in minority communities helps draw minority study participants to the clinical center.[445] In addition to developing multicultural visual and print materials, the PRPL has convened a Minority Community Leadership working group to assist in reaching local minority populations.[446]

A diverse group of clinical center employees has participated in media presentations and staffed conference exhibits aimed at reaching minority communities. These outreach activities include contact with medical communities and representatives from African American, Hispanic, and Native American populations. The continued outreach serves to educate the minority population about the value of participating in clinical research as well as to promote NIH programs to minority health care providers.[447]

Fogarty International Center

NIH's Fogarty International Center (FIC) sponsored and cosponsored several technical assistance workshops from FY 1994 to FY 1998.[448] In November 1994, the FIC in conjunction with NIH's Office of Research on Minority Health held a 2-day networking meeting to discuss the Minority International Research Training (MIRT) program's preliminary year.[449] Undergraduate and graduate students and faculty who participated in the first MIRT program discussed their experiences.[450] At the MIRT program's December 1995 meeting, the associate director of NIH's Office of Research on Minority Health discussed opportunities for minorities in science and minority health issues.[451] At a January 1996 MIRT networking meeting, the ORMH associate director for research again addressed the visions of the MIRT program, and participants gave progress reports and early self-assessments from MIRT's first 2 years.[452]

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441 Ibid.

442 Ibid., attachment

443 Kirschstein letter, attachment, p. 3.

444 Ibid.

445 Ibid.

446 Ibid.

447 Ibid.

448 Gerald T. Keutsch, director, Fogarty International Center, National Institutes of Health, HHS, memorandum to John Ruffin, associate director for Research on Minority Health, National Institutes of Health, HHS, Jan. 20, 1999 (re: study of HHS by the USCCR), attachments.

449 HHS, National Institutes of Health, Fogarty International Center for the Advanced Study in the Health Sciences, Minority International Research Training Program Network Meeting, Nov. 3 and 4, 1994, Agenda.

450 Ibid.

451 HHS, National Institutes of Health, Fogarty International Center for the Advanced Study in the Health Sciences, Minority International Research Training Networking Meeting Planning Conference, Dec. 7, 1995, Meeting Agenda.

452 Ibid.

Health Care Financing Administration

Although most operating divisions have established offices of minority health, the Health Care Financing Administration (HCFA) has chosen not to do so. Nor has an office of women's health been established. Instead, individuals have been assigned to perform some of the roles a potential office would have. HCFA has implemented or collaborated on a few effective programs, and in FY 1998, it allocated $950,000 for minority health activities, as well as other resources to support minority initiatives.[453]

Minorities Beneficiaries Work Group

HCFA formed the Minorities Beneficiaries Work Group in 1996; it includes representatives from the various components within HCFA. HCFA management decided that the different HCFA components, including HCFA centers, regional offices, and consortiums, would implement the six initiatives as they fall under their respective missions and structures.[454] HCFA management believed that this approach would be better than establishing a centralized office. All HCFA components would participate in the process and share the responsibility for minority projects.[455]

Women's Health Liaison

In 1998 the chief medical officer in HCFA's Office of Strategic Planning was assigned to women's issues part-time, as the women's health liaison.[456] The women's health liaison admits that her role is in the developmental stage. She has no policymaking authority and sees her role as an "advisor," who is gaining expertise in initiating projects and grants at HCFA.[457]

Currently, there is no other staff assigned to the area, and no budget for carrying out the coordinator's responsibilities.[458] The women's health liaison attributes her limited responsibilities and resources to the lack of administrative and managerial support for a strong women's health component at the agency.[459]

In 1998 the women's health liaison created a Women's Health Workgroup at HCFA that includes representatives from the operating division's components, including its consortiums and regions.[460] The group meets monthly to share ideas and set a course of action for women's health initiatives.[461] Currently, the liaison represents HCFA on departmental committees affecting women's issues, chairs the HCFA work group on women, and is HCFA's women's representative or liaison with other operating divisions and HHS offices.[462] She estimates that, on average, she spends about one and a half days a week performing duties as the women's health liaison. Her duties usually include conducting the monthly meetings with the HCFA work group, attending meetings with other departmental/HCFA staff, preparing speeches on women issues for the administrator, and doing some research on women's issues. However, she notes that her research on women's issues usually is related to her regular duties.[463]

The women's health liaison stated that although she serves on departmental committees and meets with other HHS offices, she had never heard of the HHS Office for Civil Rights until she received information on the Commission's health care study.[464] She also stated that she does not work regularly with any other civil rights offices or staff.[465]

According to the women's health liaison, HCFA has a huge data system, particularly with re-

[453] Ramon Suris-Fernandez, director, Office of Equal Opportunity and Civil Rights, Health Care Financing Administration, HHS, memorandum to Frederick D. Isler, assistant staff director for Civil Rights Evaluation, USCCR, Jan. 29, 1999 (re: response to information request), attachments, p. 1 (hereafter cited as HCFA, Response to Information Request).

[454] Richard Bragg, Office of Strategic Planning, Health Care Financing Administration, HHS, telephone interview, Mar. 25, 1999, p. 2 (hereafter cited as Bragg interview).

[455] Pam Gentry, senior advisor to the administrator on Special Initiatives, Health Care Financing Administration, HHS, telephone interview, Apr. 8, 1999, p. 1 (hereafter cited as Gentry interview).

[456] Marsha Davenport, women's health liaison, Health Care Financing Administration, HHS, telephone interview, Mar. 25, 1999, p. 1 (hereafter cited as Davenport interview).

[457] Ibid., pp. 1–2.

[458] Ibid. Dr. Davenport is the only minority female physician currently employed at the agency.

[459] Ibid., p. 2.

[460] Ibid., p. 1.

[461] Ibid.

[462] Ibid., pp. 1–2.

[463] Ibid., p. 2.

[464] Ibid., p. 3.

[465] Ibid., p. 2.

spect to medicaid and medicare information. She said there is great potential in using the data in developing women and minority health issues, but no indepth analysis of the data is being done.[466] Whatever statistics are provided on the use of services by women are generated from HCFA's budget office. Often the women's health liaison does not receive the computer document directly from that office.[467] She said the potential to enhance women's health issues at HCFA, through data analysis and research initiatives and projects, is hampered due to lack of real managerial support or commitment to include women's health issues as a top priority or to expand women's health perspectives or concerns at the agency.[468]

Women's Health Initiative

In 1997 HCFA released a report to educate the public and the health care community about mammography services covered by medicare and to encourage women to use these services.[469] Based on medicare data, the report presents three major findings: Only 39 percent of women aged 65 or older received mammograms during 1994–95; African American women had lower mammography rates than white women; and the use of mammography decreased substantially with age.[470] However, there is a paucity of additional HCFA projects related to women's issues.

Minority Health Coordinator

The minority health coordinator, in the Office of Strategic Planning, is assigned full time to that office's minority projects. His activities have centered on enhancing the participation of HBCUs and implementing the Hispanic Agenda for Action, with some activities to promote cultural competence and highlight race initiatives. The minority health coordinator said that he thinks his role is informal and that he is not a senior staff person who can make policy.[471]

Minority Health Initiatives

In 1998 HCFA announced the availability of funds under its program to encourage Hispanic investigators to conduct health services research. Hispanic researchers would become involved in the research projects that address health care issues such as financing, delivery, and access, as well as barriers affecting the health care of Hispanic American communities.[472] Currently, almost 40 Hispanic institutions have been contacted by HCFA for grants and technical assistance.[473]

Senior Advisor on Special Initiatives

In January 1999, the administrator of HCFA appointed a senior advisor to the administrator on special initiatives.[474] The senior advisor serves as both the coordinator and liaison between the Office of the Administrator and the HCFA components that implement the minority initiatives. She chairs the HBCU initiative and is a representative on the Department Minority Initiative Coordinating Committee. She also chairs the informal committee of HCFA staff who are responsible for implementing the initiatives within their respective components.

The senior advisor believes the strategy used in implementing the initiatives at HCFA is fragmented.[475] For example, the senior advisor for the Asian American/Pacific Islander initiative is in Boston, the senior advisor for the American Indian/Tribal Colleges and Universities initiative is in Denver, the senior advisor for the Race initiatives is in Atlanta, and the senior advisor for the HBCUs is in Baltimore. The administrator's senior advisor meets monthly with

[466] Ibid., p. 3. *See also* HCFA, Response to Information Request, Q. 15, the Enrollment Data Base (EDB) Race and Ethnicity Update. The EDB is HCFA's database for medicare beneficiary enrollment information. It is the authoritative source for medicare beneficiary information, entitlement, etc. The EDB has information on all medicare beneficiaries. HCFA, Response to Information Request, attachment: *Directory of Minority Health and Human Services Data*, September 1995.

[467] Davenport interview, p. 3.

[468] Ibid., p. 3.

[469] HHS, Health Care Financing Administration, *1994–1995 Mammography Services Paid By* Medicare: *State and County Rates*, October 1997.

[470] Ibid.

[471] Bragg Interview, pp. 2–3.

[472] HHS, Health Care Financing Administration, Office of Strategic Planning, "Announcement: 1998 Hispanic Health Care Services Research Program," undated.

[473] HCFA, Response to Information Request, attachment: "Organizations and Groups Contacted by HCFA to Receive Health Services Grant Opportunities, Technical Assistance, Conference Information and Outreach Activities."

[474] Gentry interview, p. 1.

[475] Ibid., p. 2.

the other staff senior advisors.[476] According to the administrator's senior advisor, at this time there is no support for a central office by the agency's administration.[477] The senior advisor is overwhelmed trying to keep up with all the minority activities and noted that she is not aware of everything that is being done in this area.[478]

Minority Initiatives

In 1995 the HHS Office of Minority Health and HCFA entered into an interagency agreement to operate three regional training centers for HBCUs to enhance the opportunities for these institutions to receive Federal funds and to facilitate HHS and HBCU working relationships.[479] As part of the agreement, HCFA agreed to transfer $500,000 to the OMH and to participate in training sessions to be held for HBCUs that have an interest in competing for HCFA funds.[480] HCFA also initiated a technical assistance program on the access and use of medicare/medicaid data by HBCUs. The purpose of the contract is to enhance the capacity of HBCU faculty members and researchers to participate in HCFA program activities.[481]

In 1998 HCFA increased funds to help HBCUs do health services research and demonstration projects.[482] Under this grant program, eligible HBCUs may request $100,000 to $125,000 per year for 1 to 2 years for various health services research projects.[483] Approximately 50 HBCUs have been contacted by HCFA to receive health services grant opportunities and technical assistance information.[484]

Also in 1998, each operating division was asked by the Deputy Assistant Secretary for Minority Health to participate in the compilation of a Cultural Competence Activities inventory and to develop a portfolio of practices in cultural competence training and service delivery. HCFA assigned its deputy administrator as the contact for cultural competence activities and to develop operating models on how to make medicare customer service more responsive to the needs of diverse groups.[485] HCFA also plans to:

- Establish formal consultation relationships with American Indian/Alaska Native governments.
- Assign a work group to set standards for customer services and mechanisms to measure the success in meeting the needs of diverse groups.
- Establish partnerships with other HHS components to carry out other minority initiatives.
- Enhance the participation of HBCUs and Hispanic institutions in its health services grants program.
- Sponsor conferences and symposiums that include members of racial and ethnic minority communities.[486]

HCFA has provided training on cultural awareness, and a cultural competence course is being planned.[487]

In implementing the Asian American and Pacific Islander initiative, HCFA's San Francisco and Seattle regional offices plan to establish partnerships with Asian American communities and perform outreach on the Medicare-Choice program.[488] The administrator's inventory also stated that there are Spanish versions of five of its publications on medicaid services, and that

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[476] Ibid.

[477] Ibid.

[478] Ibid.

[479] HHS, Health Care Financing Administration, "Interagency Agreement Between Office of Minority Health OASH, and Health Care Financing Administration," "Regional Training Centers for HBCUs," OMH # 95–R49, Sept. 28, 1995.

[480] Ibid.

[481] HHS, Health Care Financing Administration, Office of Research and Demonstrations, "Technical Assistance Program on Accessing and Utilizing HCFA's Medicare/Medicaid Data for Historically Black Colleges and Universities (HBCUs) Faculty Members and Researchers," Sept. 27, 1996.

[482] HHS, Health Care Financing Administration, Office of Strategic Planning, "Historically Black Colleges and Universities Grants Program," undated.

[483] Ibid.

[484] HCFA, Response to Information Request, attachment: "Organizations and Groups Contacted by HCFA to Receive Health Services Grant Opportunities, Technical Assistance, Conference Information and Outreach Activities."

[485] HCFA, Response to Information Request, attachment, Q. 14, Cultural Competence Activities Inventory.

[486] Ibid.

[487] Ibid.

[488] Ibid.

its Health of Seniors Survey is available in Chinese and Spanish.[489]

In January 1999, the director of HCFA's Division of Advocacy and Special Issues submitted information to HCFA's Office of Equal Opportunity and Civil Rights on projects related to minorities that have been implemented within that office. He listed outreach activities through meetings and conferences with representatives from various minority communities, and the development of focus groups with African American, Alaska Native, and Hispanic members who are medicaid beneficiaries and potential beneficiaries of the Children's Health Insurance Program to involve fathers in the health care of their children.[490]

Other Initiatives for Minority Researchers

HCFA's Office of Strategic Planning supports several programs designed to increase opportunities for minority researchers and faculty members. Such programs include: (1) the Health Services Research Grant Program, which supports research programs at Historically Black Colleges and Universities; (2) the Hispanic Health Services Research Grant Program, which aims to increase the number of Hispanic researchers in health services research; (3) the Data Users Conference Program, which assists HBCU faculty members in accessing and analyzing HCFA data sets; and (4) the HCFA/OMH Health Services Sponsored Program, which familiarizes HBCUs with Federal grant-making institutions and financial management policies for Federal grants.[491]

Health Resources and Services Administration

The Health Resources and Services Administration (HRSA) has taken a comprehensive approach to addressing women's and minorities' health issues, recognizing all facets of health care from education to service delivery to research. HRSA is charged with increasing access to basic health care for those who are medically underserved and has implemented more than 80 initiatives designed to "increase access to care, improve quality, and safeguard the health and well-being of the Nation's most vulnerable populations."[492] Even with the limited resources devoted to these issues, the scope of HRSA's activities appears widespread, as those responsible for oversight ensure that women's and minorities' health concerns are integrated into its general function.

Office of Women's Health

The Office of Women's Health (OWH) has a staff of three—a senior advisor for Women's Health, a professional analyst, and a staff assistant.[493] The senior advisor reports directly to the HRSA administrator, and the office is not authorized to conduct any specific programmatic activities related to women's health.[494] The senior advisor stated that she has not approached management about the possibility of HRSA/OWH obtaining programmatic authority because she believes that her authority, in terms of "policy coordination," is sufficient to direct and help identify gaps in and address women's health issues.[495] The senior advisor reviews documents and plans put forth by HRSA and HHS to ensure that these entities are "addressing issues from a gender perspective."[496]

The senior advisor chairs HRSA's Women's Health Coordinating Committee, which meets monthly to review literature, discuss issues, and plan national conferences.[497] Because HRSA/OWH is responsible for providing guidance throughout HRSA on women's health issues, the senior advisor apprises the members of the committee of current women's health issues and activities pertaining to HHS and to the larger

[489] Ibid.

[490] HCFA, Response to Information Request, attachment: "A HCFA Study—INFORMATION."

[491] "Get a Handle on Data and Improve Research with HCFA Guidance," *Closing the Gap*, May/June 1999, p. 13.

[492] Claude Earl Fox, administrator, Health Resources and Services Administration, HHS, letter to Frederick D. Isler, assistant staff director for Civil Rights Evaluation, USCCR, July 1, 1999 (re: comments on draft report), p. 1 (hereafter cited as Fox letter).

[493] Betty Hambleton, senior advisor for Women's Health, Health Resources and Services Administration, HHS, telephone interview, Mar. 19, 1999, p. 1 (hereafter cited as Hambleton interview). However, Ms. Hambleton stated that because of her title, senior advisor, it is difficult to determine within the structure of HRSA that a fully functioning, independent office exists with respect to women's health policies and activities.

[494] Ibid., p. 2.

[495] Ibid.

[496] Ibid.

[497] Ibid., p. 3.

women's health community in the Federal Government and beyond.[498] She also identifies opportunities for collaboration with other operating divisions. For instance, HRSA/OWH examines the NIH's research agenda as it is developed.[499]

According to the senior advisor, "cultural competence is the common thread" of all HRSA programs because of the diversity of populations affected.[500] In her view, one of the critical elements of cultural competence is the need for individuals to have a "sense of communicating" with persons from a wide variety of racial/ethnic backgrounds, as well as a full understanding of and respect for different populations.[501] In an effort to address cultural competence, the senior advisor is collaborating with HRSA's Office of Minority Health to develop a training module for HRSA's managers, supervisors, and bureau and division directors so that they can have "a greater awareness and skill in cultural issues."[502] The training session will also address women's issues and the "dynamics of interacting with women" on health care.[503]

In 1998 the HRSA Women's Health Coordinating Committee provided guidance and assistance in defining and implementing HRSA's women's health agenda.[504] Members of the committee act as coordinators who work with HRSA's other components on programs and activities to carry out the agenda. Members also perform outreach, which fosters greater awareness of women's health needs among other Federal programs, professional organizations, and the communities that HRSA serves.[505]

[498] Ibid.

[499] Ibid.

[500] Ibid., p. 6.

[501] Ibid.

[502] Ibid. In July 1999, HRSA reported to the Commission that it was implementing a diversity initiative as a "system of training activities for managers, supervisors, field personnel, and workforce." HRSA intends training to provide managers with knowledge to incorporate diversity factors in grant programs to further ensure access to health care programs, training, and research for minorities and women. Fox letter, p. 3.

[503] Ibid.

[504] HHS, Health Resources and Services Administration, *Agenda for Women's Health*, no date, p. 2.

[505] Ibid., p. 1.

To facilitate its role in reducing access barriers and improving the status of health care for all vulnerable populations, HRSA issued an Agenda for Women's Health.[506] This initiative seeks to improve the agency's programs and policies on the health needs of women. The agenda establishes HRSA's role in women's health through an integrated approach that includes education and training, health services, and research and evaluation.[507] The education and training goals include increasing integration of women's health issues and training of the health profession work force, participation of women in health professions, with particular attention given to women of color, and participation of women in leadership positions in health education, practice, research, and administration.[508] The health services goals include improving access for women to primary, preventive, and mental health services, and improving understanding of the roles of health care providers in the delivery of women's health care.[509] The research and evaluation goal is to improve the capacity to develop and disseminate information affecting the health of the women served by HRSA programs.[510] The goals and priorities are grounded in the need to: (1) produce a health professions work force skilled in providing quality primary and preventive health care to women; (2) educate women about their health risks and benefits; and (3) improve access for women to gender-specific, culturally competent health services within a changing health delivery system.[511]

Office of Minority Health

HRSA's major agency component for coordinating activities targeted for minorities is the Office of Minority Health (OMH),[512] which re-

[506] Ibid.

[507] Ibid.

[508] Ibid., p. 2.

[509] Ibid.

[510] Ibid.

[511] Ibid., p. 1.

[512] In 1994 one of HRSA's bureaus, the Bureau of Primary Health Care, established a staff-run Office of Minority and Women's Health to improve the health care of underserved minorities and women served by the bureau's programs. The office serves as a think tank and advisor for the bureau's director, and is a repository for up-to-date information on issues affecting women and ethnic/racial populations. Since

ports directly to the HRSA administrator.[513] Activities that address health issues of minority populations across the board include the Minority Management Development program and HRSA's committees designed to address minority health issues. The Minority Management Development Program is a public-private partnership funded by HRSA, HCFA, other Federal agencies, and the American Association of Health Plans and its member health organizations. The project is a 10-month fellowship program designed to increase the representation of minority managers and administrators in the managed care industry. Managerial training, work experience, and knowledge of the industry through training opportunities are provided for project participants. Upon completion of the program, fellows are provided with placement assistance within the health care industry. Since its inception in 1992, 76 fellows have graduated from the program.[514]

The OMH also is charged with implementing four departmental minority health initiatives that target African Americans, Hispanic Americans, American Indians/Alaska Natives, and Asian Americans/Pacific Islanders. OHM also is the lead office on HRSA's Initiative to Prevent Family and Intimate Partner Violence, which focuses on abuse against women.[515]

HRSA has an administrator's Minority Health Advisory Committee and a Cultural Competency Committee chaired by HRSA/OMH. The committees develop recommendations for improving program and coordination of minority health initiatives across HRSA.[516]

The Office of Minority Health has the leadership role at HRSA for implementing the HHS Initiative to Eliminate Racial and Ethnic Disparities in Health and has provided funds to majority and minority institutions to increase the number of racial/ethnic minorities in health profession programs. As part of this initiative, in FY 1996, HRSA began the first phase of a multitiered project, managed through its OMH, which will eventually result in a tracking/management information system that can be used by the agency to assess and improve the performance of its minority training programs.[517]

In 1997 HRSA/OMH initiated two new projects to enhance the participation of African American medical colleges in HRSA-supported health professions training programs.[518] One of the projects focuses on "capacity building and targeted technical assistance," and the other is an outreach campaign to increase HBCUs' awareness of HRSA activities.[519]

The Office of Minority Health also represents HRSA in partnerships with other operating divisions, other Federal components, health profession institutions, academic health centers, and the private sector for the Hispanic Agenda for Action.[520] The Office of Minority Health also represents HRSA in implementing the newly instituted American Indian/Alaska Native Tribal Initiative. The initiative has involved, for the most part, outreach and networking through a satellite broadcast on nursing programs in collaboration with the Indian Health Service and the Salish Kootenai Community College, conferences, and the development of a steering committee.[521]

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its inception, the office has grown from two to nine employees. HHS, Health Resources and Services Administration, Bureau of Primary Health Care, "Office of Minority and Women's Health, Bureau of Primary Health Care," Dec. 28, 1998, pp. 1–9, accessed at <http://www.bphc.hrsa.dhhs.gov/omwh/omwh_ 20.htm#2>.

[513] Claude Earl Fox, administrator, Health Resources and Services Administration, HHS, memorandum to Frederick D. Isler, assistant staff director for Civil Rights Evaluation, USCCR, Jan 29, 1999 (re: response to information request) (hereafter cited as HRSA, Response to Information Request), attachment: Office of Minority Health Mission Statement.

[514] HRSA, Response to Information Request, attachment: "Office of Minority Health Programs Benefiting Women and Minorities," p. 1.

[515] Ibid.

[516] Ibid.

[517] Ibid., p. 2.

[518] Ibid., p. 3. This project is supposed to conduct a comprehensive analysis of the declining level of HRSA programs to the four African American medical schools (Morehouse School of Medicine, Howard University School of Medicine, Meharry Medical College, and the Charles R. Drew University of Medicine and Science) and to develop recommendations that will reverse the trend. Ibid.

[519] HHS, Health Resources and Services Administration, "Office of Minority Health Projects and Initiatives," Mar. 20, 1997, p. 3, accessed at <http://www.hrsa.gov/hrsa/OMH/omhproj.htm>.

[520] HRSA, Response to Information Request, attachment: "Office of Minority Health Programs Benefiting Minorities and Women," pp. 3–4.

[521] Ibid., p. 5.

For HHS' activities connected to the Tribal College and Universities Initiative, OMH has the lead role in developing a coordinated response to Executive Order 13021.[522] The Office of Minority Health is collaborating with bureaus and offices to devise approaches to ensure that tribal postsecondary education institutions have increased accessibility to Federal resources on a continuous basis. OMH is also implementing HRSA's Action Plan for Tribal Consultation, to strengthen relationships with American Indian and Alaska Native customers and to devise a strategy to address their needs.[523]

HRSA spearheaded a departmentwide effort to form the free-standing National Association of Hispanic-Serving Health Professional Schools, whose members are health professions schools with a Hispanic enrollment of at least 9 percent.[524] HRSA claims that the underrepresentation of Hispanics in the health professions is a well-documented problem that could jeopardize Hispanic Americans' health status; and that a concerted effort within HHS is essential to address the critical shortage of Hispanic health care workers.[525] OMH was charged with convening presidents of health sciences centers, deans of medical schools, and administrators in institutions serving high concentrations of Hispanics to form a national association that develops strategies to expand the number of Hispanics in health professions and establishes links with public elementary and secondary schools.[526] Currently, OMH provides technical assistance to the National Association of Hispanic-Serving Health Profession Schools, which was incorporated in 1996 as a nonprofit organization.[527] The partnership among the Federal Government, health profession institutions, academic health centers, and the private sector is striving to ensure that a sufficient supply of Hispanics are in the health care work force by the 21st century.[528] An understanding of Hispanic health issues and cultural competency will be an essential tool for trained professionals to meet the needs of the Nation's growing Hispanic population.[529]

Under the Asian /Pacific Islanders and Native American Initiative, the Office of Minority Health was one of the first offices in HRSA to initiate efforts to meet the health care needs of this community. Activities have included developing strategies for implementing the initiative and sponsoring a national conference with Asian American and Pacific Islander leaders in March 1998 to develop an action plan.[530]

The Women's Preventive Health Branch of OMH developed a training program for health care providers in rural communities where most migrant workers reside to increase the number of health care staff who can communicate with limited-English-proficient persons. HRSA authorizes States to disseminate grant funds to rural, medically underserved communities with many limited-English-proficientresidents.[531] States can use the grant funds to build health care providers' skills in conducting medical histories and nutrition and HIV counseling and to improve their knowledge about sociocultural and health factors related to specific ethnic populations.[532]

OMH also provides State grant funds for multicultural projects, which include interpreter services for low-income and immigrant communities, and training workshops at local health departments in growing multiethnic districts.[533] These projects allow primary and preventive health care providers to improve their knowledge on particular genetic disorders, and enhance the quality and effectiveness of their communication with limited-English-proficient clients.[534]

Bureau of Primary Health Care. Aside from initiating programs that target the individual minority initiatives, HRSA has programs that serve as health care umbrellas for the Nation. For example, the National Health Service Corps (NHSC), a program of HRSA's Bureau of Pri-

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[522] HRSA, "Minority Health Initiatives," p. 4.

[523] Ibid.

[524] Report of Working Group on Hispanic Issues, p. 6.

[525] HRSA, "Minority Health Initiatives," p. 2.

[526] Ibid.

[527] Ibid.

[528] Ibid.

[529] Ibid.

[530] HRSA, Response to Information Request, attachment: "Office of Minority Health Programs Benefiting Minorities and Women," p. 5.

[531] HHS, response to recommendations cited in *Civil Rights Issues Facing Asian Americans in the 1990s.*

[532] Ibid.

[533] Ibid.

[534] Ibid.

mary Health Care, assists underserved communities through the development, recruitment, and retention of community-responsive, culturally competent primary care professionals dedicated to practicing in areas with a shortage of health professionals.[535] HRSA provides scholarships and loans to disadvantaged students enrolling in health professions training programs and schools. In exchange for tuition assistance or loan repayment, health care professionals in the National Health Service Corps are placed in underserved areas for the duration of their service commitment.[536]

The NHSC is a culturally diverse team of 2,300 primary care professionals who provide quality care to 4.6 million people, who would otherwise lack adequate access to health services.[537] NHSC serves people of every age, race, and ethnic background with diverse health needs.[538]

Bureau of Health Professions. HRSA's Bureau of Health Professions sponsors 132 Health Careers Opportunity Programs, which introduce high school and undergraduate students to health professions schools. Through these programs, students meet minority health professionals, learn about health care careers, and participate in academic enrichment programs.[539] According to HRSA, the students who participate in these programs are accepted into health professional schools at a higher rate than the national average.[540]

In one program, Partnerships for Health Professions Education, health educators work with local health care providers, schools, and other partners to encourage students to enter the health professions.[541] The HRSA administrator said, "Beginning in elementary school, the partnerships build awareness of health professions and make sure minority children see minority health care providers in action. Summer science programs and camps, even health care magnet school programs encourage and prepare young people for health professions training."[542]

Maternal and Child Health Bureau. HRSA's Maternal and Child Health Bureau is primarily responsible for promoting and improving the health of mothers, infants, children, adolescents, and families with low incomes, of diverse racial and ethnic groups, and in rural or isolated areas with little access to health care.[543] The Bureau administers four major programs: the maternal and child health services block grant, the Healthy Start Initiative, the emergency medical services for children program, and the abstinence education program.[544]

Two of the Maternal and Child Health Bureau's programs in particular address the needs of underserved populations. The maternal and child health block grant program is specifically involved in initiatives aimed at reducing infant mortality, providing health care for women at all stages of pregnancy and childbirth, immunizing children, and improving the nutritional and developmental needs of families.[545] In addition, the Healthy Start Initiative funds programs aimed at reducing infant mortality in high-risk communities.[546]

HIV/AIDS Bureau. HRSA's HIV/AIDS Bureau administers funds for intervention, treatment services, and research on the disease. In particular, the Bureau funds programs that focus on the provision of primary health care for children and women living with HIV and their families.[547] Many of the services funded by the Bureau are community based and comprehensive; services include outpatient health care, case management, home health, hospice care, and transportation assistance.

The HIV/AIDS Bureau also houses the Special Projects of National Significance Program,

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[535] Health Resources and Services Administration, Bureau of Primary Health Care, *National Health Service Corps*, GE149E, June 23, 1997 (hereafter cited as HRSA, *National Health Service Corps*).

[536] Claude Earl Fox, "HRSA Opens Doors for Minorities in Health Professions," *Closing the Gap*, May/June 1999, p. 3.

[537] HRSA, *National Health Service Corps.*

[538] Ibid.

[539] Fox, "HRSA Opens Doors," p. 2.

[540] Ibid.

[541] Ibid.

[542] Ibid.

[543] HHS, Health Resources and Services Administration, Maternal and Child Health Bureau, "Maternal and Child Health Bureau—Overview," accessed at <http://www.mchb.hrsa.gov/overview.htm>.

[544] Ibid.

[545] Ibid.

[546] Ibid.

[547] HHS, Health Resources and Services Administration, HIV/AIDS Bureau, fact sheet, accessed at <http://www.hrsa.dhhs.gov/hab/OC/factshee/hab.htm>.

which supports the development of innovative models of health care designed to address the special needs of individuals with HIV/AIDS in minority and hard-to-reach communities.[548] In an effort to reach populations with high rates of HIV/AIDS infection, the Bureau has established AIDS education and training centers in designated geographic regions to increase the number of health care professionals with expertise in diagnosis, counseling, and treatment of HIV/AIDS patients. Since 1991, more than 700,000 providers have been trained by this program.[549]

Substance Abuse and Mental Health Services Administration

Office of Minority Health and Office of Women's Health

The Substance Abuse and Mental Health Services Administration (SAMHSA) has an Office of Minority Health, which advises SAMHSA components on initiatives on access and delivery of services to racial/ethnic minorities who suffer disproportionately from substance abuse and mental illness.[550] The office also provides leadership and coordination for addressing specific substance abuse and mental health issues of racial and ethnic minority populations.[551]

In 1994 and 1995, SAMHSA's organizational structure also included an Office for Women's Services with an associate administrator for Women's Services, but that office no longer exists.[552] As a result of reorganization, SAMHSA's associate administrator for Women's Services now serves as the team leader for the Women, Children, and Families Team, which is located in the Office of Policy and Program Coordination.[553]

Reports and Other Activities Related to Minority and Women's Initiatives

SAMHSA's components and grantees have developed standards and have prepared studies, reports, and manuals on substance abuse and mental health services for women and different racial and ethnic minority groups. For example, SAMHSA funded a project to develop cultural competence standards in managed care for five underrepresented racial/ethnic groups.[554] The standards were developed as a result of four national panels, with representatives from the five groups.[555] According to the project's final report, "Cultural competence includes attaining the knowledge, skills, and attitudes to enable administrators and practitioners within systems of care to provide effective care for diverse populations, i.e., to work within the person's values and reality conditions."[556] Cultural competence acknowledges differences in behaviors, beliefs, and values in determining an individual's mental wellness, and in incorporating those variables into assessment and treatment.[557] The document presents 16 guiding principles for attaining cultural competence in health care, including principles for community-based system care, managed care, and for collaboration and empowerment.[558] The report also includes the components

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548 Ibid.

549 Ibid.

550 Nelba Chavez, administrator, Substance Abuse and Mental Health Services Administration, HHS, letter to Frederick D. Isler, assistant staff director for Civil Rights Evaluation, USCCR, Jan. 13, 1999 (re: request for information), p. 8 (hereafter cited as SAMHSA, Response to Information Request). *See also* ibid., attachment: Organizational Chart. From SAMHSA's documents that show its organizational structure from 1994 to 1998. SAMHSA's Office of Minority Health first appears on the agency's Organizational Chart dated Dec. 22, 1997.

551 SAMHSA, Response to Information Request, attachment, tab 3, mission and function statements, p. 8.

552 SAMHSA, Response to Information Request, attachment Organizational Charts.

553 Nelba Chavez, administrator, Substance Abuse and Mental Health Services, HHS, letter to Frederick D. Isler, assistant staff director for Civil Rights Evaluation, USCCR, July 9, 1999 (re: comments on draft report), p. 1 (hereafter cited as Chavez letter).

554 HHS, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services, *Cultural Competence Standards in Managed Mental Health Care for Four Underserved/Underrepresented Racial/Ethnic Groups: Final Report from Working Groups on Cultural Competence in Managed Mental Health Care,* prepublication copy, October 1997. The document was prepared through the Western Interstate Commission for Higher Education Mental Health Program with SAMHSA's Center for Mental Health Services, Division of Special Programs Development and Special Populations, Special Program and Development Branch, HHS. The five racial/ethnic groups were African American, Asian/Pacific Islander, Latino/Hispanic, Native American/American Indian, and Native Alaskan/Native Hawaiian.

555 Ibid., p. v.

556 Ibid., p. 19.

557 Ibid.

558 Ibid., pp. 19–22, 28–30.

of a cultural competence plan, 14 guidelines for implementing the plan, and recommendations for performance indicators and outcomes for such a plan.[559]

In a speech delivered at a health conference in Michigan in 1997, the administrator of SAMHSA called on the Nation's health administrators to ensure that cultural competency becomes a standard part of medical training.[560] She stressed that developing a "thoughtful policy" to provide cultural sensitivity training to health professionals and to provide Hispanic/Latino women and other women of color (as recipients of HHS programs) with more health information and greater involvement in health research would require the "active participation" from groups that have been traditionally excluded from the discussions and research.[561] In 1998 SAMHSA received positive feedback for broadcasting a discussion of its household survey on all Spanish-language networks.[562] To further the HHS goal of reducing the gaps in the provision of health care services to Hispanics, SAMHSA has awarded grants to the U.S.-Mexico border States to provide prevention and early intervention services for substance abuse to Latino youth and families.[563]

In 1998 SAMHSA released its first report on national estimates of drug, alcohol, and tobacco use, and need for drug abuse treatment for racial/ethnic subgroups, including Asian/Pacific Islanders, Native Americans, Caribbean Americans, non-Hispanic blacks, Central Americans, Cuban Americans, Mexican Americans, Puerto Ricans, South Americans, and other Hispanic Americans.[564] The report was based on the agency's National Household Survey on Drug Abuse which is conducted annually by SAMHSA and provides estimates of the prevalence of illicit drug, alcohol, and tobacco use in the United States.[565] The report analyzes racial and ethnic patterns of substance abuse, using a more detailed classification of race/ethnicity than had been done previously by the agency.[566] The findings of the report suggest that "social, demographic and economic differences among the subgroups studied to some extent influence levels of substance use, alcohol abuse and dependence, and need for drug abuse treatment."[567]

SAMHSA has also focused on these issues as they affect women. In FY 1997, SAMHSA's Center for Substance Abuse Treatment provided funds to support 65 grant projects for residential substance abuse treatment for women and their infants and children nationwide. The center released a document that provides a general overview of and descriptive information about each project, including contact information for each project site.[568] SAMHSA, the Office of Applied Studies, and the National Opinion Research Center prepared the first systematic effort to study alcohol, cigarette, and illicit drug use in a sample of women aged 12 and older.[569] Using data from 1979–1995 National Household Surveys on Drug Abuse, the report shows trends and patterns of substance abuse and use among women, including pregnant women, use of treatment services among female drug abusers, and characteristics of women who did not receive treatment within the criminal justice system.[570]

In 1994 SAMHSA's Center for Substance Abuse Treatment, Division of Clinical Programs' Women and Children's Branch, released a comprehensive document for substance abuse treatment providers on substance abuse treatment of women.[571] The manual is a guide to developing and implementing effective substance abuse

[559] Ibid., pp. 25–27.

[560] HHS, Hispanic Initiative Press Release.

[561] Ibid.

[562] Hispanic Agenda for Action Steering Committee, July 16, 1998, Meeting Summary, p. 1.

[563] Clay E. Simpson, Jr., "Reaffirming Our Commitment to Improving Health Services for Hispanics," *Closing the Gap*, October 1998, p. 3.

[564] HHS, Substance Abuse and Mental Health Services Administration, Office of Applied Studies, *Prevalence of Substance Use Among Racial/Ethnic Subgroups in the United States, 1991–1993*, April 1998, pp. 1–2.

[565] Ibid., pp. 1–2, 5–6.

[566] Ibid., p. 7.

[567] Ibid., p. 2.

[568] *See* HHS, Substance Abuse and Mental Health Services Administration, Center for Substance Abuse Treatment, *Center for Substance Abuse Treatment Women & Children's Program Grantees: Project Summaries 1997.*

[569] *See* HHS, Substance Abuse and Mental Health Services Administration, Office of Applied Studies, *Substance Use Among Women in the United States*, September 1997, p. iii.

[570] Ibid., pp. iii.

[571] *See* HHS, Substance Abuse and Mental Health Services Administration, Center for Substance Abuse Treatment, Division of Clinical Programs, Women and Children's Branch, *Practical Approaches in the Treatment of Women Who Abuse Alcohol and Other Drugs*, 1994.

treatment services for women and includes a cross-section of women.[572] For example, one section presents summary epidemiologic data on several groups of women, including older women, women with disabilities, and African American, Asian/Pacific Islander, and Hispanic women.[573] In 1998 the Substance Abuse Treatment and Domestic Violence Treatment Improvement Protocol was released.[574] It presents information on the role of substance abuse in domestic violence and focuses primarily on women who are victims of violence. The document provides techniques for detecting violence as well as ways to modify treatment to ensure victims' safety, and serves as an instrument for treatment providers, support workers, and researchers.[575] Another study, the Women and Violence Study, also addresses issues of alcohol, drug abuse, mental health disorders, and violence. The study's purpose is to develop an integrated system of treatment, and then implement strategy models.[576]

In July 1994, SAMHSA's Center for Mental Health Services and the Human Resource Association of the Northeast cosponsored a conference to shape the national agenda for women in abuse and mental health services. Funded in part by a grant administered by the center, the conference included survivors, professionals, and advocates from the fields of mental health, substance abuse, and criminal justice, as well as advocates for the homeless.[577] The conference covered several topics and issues on women's health concerns in abuse and mental health services. The proceedings of the conference were presented in a report released in 1994 and reprinted in 1995.[578] In June 1999, SAMHSA hosted the Second National Conference on Women (the first of which it cosponsored with several Federal agencies in 1997), in an effort to increase interest in and commitment to women's substance abuse and mental health issues within the health and social service arenas.[579] The conference aims were to improve the delivery of mental health services for women and their families and to foster interaction among providers across disciplines.[580]

Centers for Disease Control and Prevention

Office of the Associate Director for Women's Health

At the Centers for Disease Control and Prevention (CDC), an associate director for Women's Health reports to the deputy director for Science and Public Health.[581] The mission of the office is "to provide leadership in enhancing CDC's efforts to promote and improve the health and quality of life of women."[582] In FY 1998, the office's budget was $1.12 million, and it had a staff of four.[583]

The goals of the associate director are to provide leadership that supports the full integration of women's health into disease prevention and health promotion programs at CDC and to improve the health of all women through promotion and support of prevention programs, research and policies.[584]

Through CDC's centers, institutes and offices, the Women's Health director funds projects by CDC researchers and partners in public health and academic organizations.[585] The projects include research on women's health problems such as osteoporosis, violence against women, infectious disease management, injuries, occupational-related illnesses, and health care and health promotion of women with physical disabilities.[586]

The associate director also supports activities at the State, local, national, and international levels to disseminate information on women's

[572] Ibid.

[573] Ibid., p. 35.

[574] Chavez letter, p. 1.

[575] Ibid., p. 2.

[576] Ibid.

[577] HHS, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services, Women's Mental Health Programs, *Dare to Vision*, January 1995, statement of HRA director.

[578] Ibid.

[579] Chavez letter, p. 2.

[580] Ibid.

[581] Candice Nowicki-Lehnherr, deputy director/Executive Secretariat, Centers for Disease Control and Prevention, HHS, letter to Eileen Rudert, Office of Civil Rights Evaluation, USCCR, no date (re: request for information), attachment (hereafter cited as CDC, Response to Information Request).

[582] HHS, Centers for Disease Control and Prevention, *Fact Book, FY 1998*, p. 26 (hereafter cited as CDC Fact Book).

[583] Ibid., p. 26.

[584] Ibid., p. 28.

[585] Ibid., p. 27.

[586] Ibid.

health issues; coordinates CDC activities to ensure that women's health issues are adequately addressed in research and programs; collaborates with HHS and other governmental organizations on women's issues; and chairs the CDC Women's Health Committee.[587] With respect to areas of focus for women's health initiatives at CDC, the agency concentrates efforts on such areas as breast and cervical cancers, injury and violence, sexually transmitted diseases, health in later years, and health status indicators.[588]

The CDC has established partnerships with State and local health departments, academic institutions, professional and community organizations, philanthropic foundations, school systems, churches and other local institutions, and industry and labor organizations.[589]

Inclusion of Women and Racial/Ethnic Minorities in CDC Research

In 1996 CDC set forth the agency's policy on the inclusion of women and members of racial and ethnic minority groups in intramural research conducted by CDC staff.[590] The guidelines are intended to ensure that individuals of both sexes and the various racial and ethnic groups will be included in CDC studies involving human subjects, whenever feasible and appropriate.[591] For purposes of generalizing study results, CDC investigators must include the widest possible range of population groups.[592] The guidance states conditions as to when the inclusion of such groups in the research may or may not be warranted, and offers some standards for evaluating when the inclusion of these groups should be considered.[593]

Office of the Associate Director for Minority Health

CDC's associate director for Minority Health reports to the deputy director for Science and Public Health.[594] The mission of the minority health initiative at CDC is "to improve the health of specific minority groups, including African Americans, Hispanic Americans, Asian Americans and Pacific Islanders, and American Indians and Alaska Natives, and other racial and ethnic subgroups in the United States and abroad.[595] The office has several small contracts with academic institutions, churches, national minority organizations, and community-based organizations for programmatic analysis and minority health demonstration projects.[596]

The Office of Associate Director for Minority Health provides leadership, assessment, advocacy, coordination, and evaluation of minority health activities of CDC centers, institutes, and program offices in cooperation with State and local governments and private agencies, organizations, and community groups.[597] Many initiatives target CDC research and programs to health conditions that disproportionately affect racial and ethnic minorities.

Activities include the dissemination of data on minority health conditions; the development of minority health education in historically black colleges and universities; the implementation of a cooperative agreement with the Minority Health Professions Foundation to analyze preventive health practices among minority health providers and foster development of research capabilities at colleges and universities; and collaboration with churches and other local entities to develop health promotion and disease prevention initiatives targeted to at-risk populations.[598]

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[587] Ibid.

[588] Ibid., p. 28.

[589] CDC Fact Book, p. 4.

[590] HHS, Centers for Disease Control and Prevention, "Inclusion of Women and Racial and Ethnic Minorities in Research," Manual Guide, General Administration CDC-80, Transmittal Notice 96.2, Feb. 16, 1996, accessed at <http://www.cdc.gov/od/foia/policies/inclusio.htm>. The guidelines originally were published in the *Federal Register* on Sept. 15, 1995. *See* 60 Fed. Reg. 47,947 (1995). *See* chap. 3.

[591] 60 Fed. Reg. 47,947 (1995).

[592] *Id.*

[593] *Id.*

[594] CDC, Response to Information Request, attachment Organizational Chart, November 1998.

[595] CDC Fact Book, p. 17.

[596] Ibid., p. 17.

[597] Ibid., p. 18.

[598] CDC Fact Book, p. 18. Some of the initiatives target infant and maternal health among African American women; chronic diseases (diabetes, heart disease, hypertension, etc.) of African Americans, Hispanics, American Indians, and Alaska Natives; HIV infection and other transmitted diseases that disproportionately affect minorities; infectious diseases; and environmental health conditions among residents of urban and rural areas, the U.S.-Mexican border area, and migrant workers in the United States. Ibid., p. 19.

CDC also cosponsors symposiums and other activities that enhance careers for minorities in biomedical sciences, manages cooperative agreements and other initiatives with HBCUs; reviews current data sources on the health conditions and status of racial and ethnic minority populations; and collaborates with departmental work groups, associations and other government agencies in developing and implementing minority-related health issues, topics, and agendas.[599]

In an effort to coordinate its data systems and enhance the quality of published information, the National Center for Health Statistics' National Health Interview Survey has expanded the level of detail for the Asian American category to collect data on Chinese, Filipino, Hawaiian, Korean, Vietnamese, Japanese, and other subgroups.[600] Other ways in which HHS has attempted to enhance the quality of published information is through the National Center for Health Statistics' Minority Health Statistics Grant Program, which is charged with improving the quality of health statistics on racial/ethnic groups, as well as determining strategies to collect detailed subpopulation data from national, State, and local surveys.[601] In 1995 NCHS awarded funds to the American Asian Health Forum, Inc., to identify existing health studies that can potentially include and/or examine Asian American ethnic groups and determine sampling methods to revise current or conduct new community-based health studies.

In 1994 the CDC released a report that presented information on chronic disease and its effect on four major racial and ethnic minority groups.[602] The document summarizes national demographic and health data related to chronic diseases in minority populations, and serves as a resource on such diseases and the associated behavioral factors found within these groups. The report includes discussions on public health implications of population diversity and growth, morbidity and life expectancy, as well as risk factors and preventive health practices affecting these groups.[603]

Food and Drug Administration

Office of Women's Health

The Food and Drug Administration's (FDA) Office of Women's Health funds research and education and outreach programs on a large number of health issues. It uses a competitive peer review process for selection of projects with an emphasis on projects that can significantly contribute to knowledge of women's health.[604] To date, FDA's Office of Women's Health has awarded approximately $6 million in grants for these projects, including more than 50 scientific projects for research on breast and ovarian cancer, cardiovascular disease in women, and women and HIV.[605]

The FDA Office of Women's Health also has education and outreach activities, including a series of minority empowerment workshops in the mid-Atlantic region, the production of a breast cancer awareness play and panel discussion in African American churches in Texas and at Howard University, a Hispanic women's health conference for health professionals in south Florida, and the translation of brochures on mammography and pap smears into several Asian languages and dialects.[606] The office also has started a public awareness program, Women's Health: Take Time to Care, aimed at bringing important health promotion messages to mid-life and older women, with emphasis on the underserved.[607] One of its missions is to encourage industry to include women in their studies and encourage the participation of women in clinical trials of FDA-regulated products.[608] The office also sponsors and attends conferences, proposes new regulations, participates

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599 Ibid., pp. 20–21.

600 HHS, response to recommendations cited in *Civil Rights Issues Facing Asian Americans in the 1990s.*

601 Ibid.

602 HHS, Centers for Disease Control and Prevention, *Chronic Disease in Minority Populations: African Americans, American Indians and Alaska Natives, Asians and Pacific Islanders, Hispanic Americans,* 1994.

603 Ibid., pp. 1–4.

604 Rosamelia T. Lecea, director, Office of Equal Employment and Civil Rights, Food and Drug Administration, HHS, letter to Frederick D. Isler, assistant staff director for Civil Rights Evaluation, USCCR, Mar. 31, 1999 (re: response to information request), enclosure #3, "FDA Office of Women's Health," Feb. 18, 1999, p. 1 (hereafter cited as FDA, Mar. 31, 1999, Response to Information Request).

605 Ibid.

606 Ibid.

607 Ibid.

608 *See* discussion in chap. 2.

on intra-agency, departmental, and outside committees that address women's scientific and policy issues, and sponsors agency initiatives for collecting and analyzing gender-specific data.[609]

Since FY 1994, the office has funded more than 88 intramural projects, including 77 scientific/regulatory projects totaling $6,722,400, and 11 health promotion programs equaling $382,000.[610] Funded projects include workshops, studies, a pilot software program, and translation of brochures and other documents for and about women in Asian and Pacific Islander languages.[611]

Indian Health Service

The Indian Health Service (IHS) is responsible for providing Federal health services to members of federally recognized American Indian and Alaska Native tribes.[612] The IHS is the principal Federal health care provider and health advocate for Indian people, and its goal is to ensure that comprehensive, culturally acceptable personal and public health services are available and accessible to American Indian and Alaska Native people.[613] The IHS partners with American Indian and Alaska Native tribes to raise the physical, mental, social, and spiritual health of their members to the highest level. To carry out its mission, the IHS:

- Assists Indian tribes in developing their health programs through activities such as health management training, technical assistance, and human resource development.
- Assists Indian tribes in coordinating health planning; in obtaining health resources available through Federal, State, and local programs; in operating comprehensive health care services; and in doing health program evaluations.
- Provides comprehensive health care services, including hospital and ambulatory medical care and preventive and rehabilitative services; and assists in developing community sanitation facilities.
- Serves as the principal Federal advocate for Indians in the health field to ensure comprehensive health services for American Indian and Alaska Native people.[614]

The IHS has numerous programs designed to reduce mortality and raise life expectancy. Some of the major health concerns of American Indians and Alaska Natives include maternal and child health needs, problems associated with aging, heart disease, alcoholism, mental health, diabetes, and accidents.[615] To address the health care needs of American Indians and Alaska Natives, IHS has designed programs, such as the diabetes program, the nutrition program, the mental health program, the community health representative program, the dental program, the accident and injury reduction program, the laboratory program, and the pharmacy program.[616]

The IHS has 43 hospitals in the United States, ranging in size from 11 to 170 beds per hospital, and several new facilities are being planned.[617] Comprehensive patient-oriented pharmacy services are provided throughout the Nation. Because alcoholism is a major health issue in the American Indian and Alaska Native

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[609] FDA, Mar. 31, 1999, Response to Information Request, enclosure #3, "FDA Office of Women's Health," Feb. 18, 1999.

[610] U.S. Food and Drug Administration, Office of Women's Health, "OWH Funding for Research and Health Promotion Programs Conducted by Center/Office Staff," Feb. 1, 1999. *See* FDA, Mar. 31, 1999, response to information request, tab A.

[611] Ibid.

[612] American Indians and Alaska Native people carry a dual status for purposes of Federal responsibilities, both political and minority based. As such, they have certain distinct protections. Although the IHS is an operating division, it is considered a "special population" agency within HHS and not a minority initiative. Michael J. Trujillo, Assistant Surgeon General, director, Indian Health Service, HHS, letter to Frederick D. Isler, assistant staff director for Civil Rights Evaluation, USCCR, July 2, 1999 (re: comments on draft report) (hereafter cited as Trujillo letter).

[613] HHS, Indian Health Service, "Indian Health Service Internet Home Page," accessed at <http://www.tucson.ihs.gov>. *See also* Trujillo letter, p. 2.

[614] Indian Health Service, "Comprehensive Health Care Program for American Indians and Alaska Natives—Mission Statement," accessed at <http://www.ihs.gov/NonMedicalPrograms/Profiles/profileMission.asp>.

[615] Indian Health Service, "Comprehensive Health Care Program for American Indians and Alaska Natives—Introduction," p. 2, accessed at <http://www.ihs.gov/NonMedicalPrograms/Profiles/profileIntro.asp>.

[616] Indian Health Service, "Comprehensive Health Care Program for American Indians and Alaska Natives—Summary Statement," p. 1, accessed at <http://www.ihs.gov/NonMedicalPrograms/Profiles/profileSummary.asp> (hereafter cited as IHS, "Summary").

[617] Ibid., p. 2.

community, the IHS has funded 200 alcoholism programs throughout the United States.[618]

Agency for Health Care Policy and Research

The Agency for Health Care Policy and Research (AHCPR) is the lead HHS agency charged with supporting, conducting, and disseminating research that improves access to care and the outcomes, quality, cost, and use of health care services.[619] AHCPR accomplishes its mission through three strategic goals: by supporting improvements in health outcomes; by strengthening quality measurement and improvement; and by identifying strategies to improve access, fostering appropriate use, and reducing unnecessary expenditures.[620] The agency's research strives to develop methods to improve the organization and delivery of health care services to improve the quality of care for racial and ethnic minority populations. Over time, AHCPR intends to shift the focus of research activities toward identifying the many types of interventions that will be necessary to eliminate gaps in health status and health outcomes for minority populations.[621]

AHCPR's Minority Health Program coordinates agency activities that address the concerns of racial and ethnic minorities. The Minority Health Coordinating Committee (MHCC) was created to facilitate communication and coordination between the offices and centers, and advise the director of AHCPR's Minority Health Program. The MHCC, the focal point for extramural and intramural activities and initiatives throughout the agency, includes one member and one alternate from each Office and Center, and the director of the Minority Health Program chairs the MHCC.[622]

Through implementation of its Minority Health Program Strategic Plan, AHCPR plans to continue increasing the knowledge base, supporting training, increasing the participation of minority constituents in AHCPR activities, and disseminating research information to minority consumer and professional organizations.[623] AHCPR has had two programs dedicated to minority care research and training:

- The Minority Supplement Program, which was initiated in fiscal year 1991 for the purpose of providing research supplements to currently funded project grants in order for the principal investigator either to expand the research in an area that address issues concerning minority populations, or to provide a training opportunity for a minority researcher. Through fiscal year 1998, AHCPR allocated $5.86 million for the training of 101 minority researchers through this activity.[624]
- The Medical Treatment Effectiveness Program (MEDTEP) Research Centers on Minority Populations Program was created to address discrepancies in health, increase the knowledge base of minority health research, and increase the number of minority health services researchers. This program was initiated in 1991, with the intention of developing research centers to conduct and support research, to provide technical assistance, to disseminate information, and to train researchers on the outcomes and effectiveness of health care services provided to minority populations.[625] Over the course of the program, AHCPR has supported a total of 11 MEDTEP Centers.[626]

AHCPR has worked with the directors of its National Research Service Award Institutional Training Programs to increase the participation of racial and ethnic minority students in the programs. Of the 472 students participating in the programs from 1993 to 1996, 18 percent were identified by the principal investigators as racial and ethnic minority students.

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[618] Ibid.

[619] John M. Eisenberg, administrator, Agency for Health Care Policy and Research, HHS, letter to Frederick D. Isler, assistant staff director for Civil Rights Evaluation, U. S. Commission on Civil Rights, June 26, 1999 (re: comments on draft report), p. 1.

[620] Ibid.

[621] Ibid., p. 2.

[622] HHS, Agency for Health Care Policy and Research, "Agency for Health Care Policy and Research Report to Congress on Minority Health Activities for Fiscal Years 1997 and 1998" (no date), pp. 1–2, executive summary.

[623] Ibid., p. 2.

[624] Ibid., pp. 1–2.

[625] Ibid., p. 2.

[626] Ibid.

State Initiatives: Minority and Women's Health Activities

Many State health agencies have implemented programs and activities targeting minorities and women.[627] With the assistance of Federal funds, States have been able to successfully implement a variety of programs. There are many possible tactics for addressing the health care issues of minority and women populations. Those listed here can be categorized to address three health care objectives: identifying disparities in health status, increasing access to care, and improving the level of health education and outreach in underserved communities. This is not intended to be an exhaustive examination of all initiatives, but rather a sample of those that have been undertaken.

In an effort to focus on these health issues, many States have created separate offices to address minorities' and women's health. For example, in October 1998, the West Virginia Department of Health and Human Services, Bureau for Public Health, started a minority health program. The program acts as a resource in assisting organizations, health care providers, government agencies, and minority communities in decreasing morbidity and mortality, increasing general wellness, and eliminating the disparities in health status and access to quality medical care.[628] The Illinois Department of Health has a Center for Minority Health Services that coordinates a Minority Health Partnership responsible for providing information and assistance on a wide range of health-related issues to improve the overall health of minorities. The State of Illinois has also established an office of women's health with the purpose of conducting an inventory of all women's health programs in the State; identifying areas of potential collaboration; and examining social, economic, psychological, and physical barriers to better health for women.[629]

Every State, several territories, and the District of Columbia have a designated women's health contact who communicates with the Office of Women's Health at HHS.[630] As many as 11 States have formally established women's health offices, some by statute, some by Executive order, either within the State health department or the Governor's office.[631] Some of the offices and contacts have significant budgets, some are formal positions, but most are collateral duty. And even when located in the State health department, the office may be at the level of the Health director, or it may be within a family planning, maternal and child health, or chronic disease division.[632]

Identifying Disparities in Health Status

Most efforts at the State level appear to be in data collection and production of reports on group-specific health issues. Almost all States that submitted materials to the Commission included information about data gathering efforts, and many States have commissioned reports on health concerns of minorities and women, including comprehensive analyses of health services and utilization rates, disease-specific data, and demographic compositions of geographical regions. These reports are essential for highlighting areas where health and health care disparities exist, and subsequently assessing where there is the greatest need for intervention.

For example, the Washington State Department of Health has issued several reports and other documents on statewide initiatives affecting women and racial and ethnic populations.[633] In October 1992, the department released the *Washington State Health Data Report on People*

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[627] Of the 37 States that responded to the Commission's request for information, 14 provided materials about specific programs that are discussed here. The Commission would like to acknowledge the remaining 23 States that responded but did not include specific information on initiatives: Alaska, Arizona, Colorado, Georgia, Iowa, Kansas, Kentucky, Louisiana, Maryland, Michigan, Mississippi, Nevada, New Mexico, New York, North Dakota, Ohio, Pennsylvania, South Carolina, South Dakota, Tennessee, and Wyoming, as well as the territories of Guam, Puerto Rico, and the Virgin Islands.

[628] Joan E. Ohl, Secretary, State of West Virginia, Department of Health and Human Resources, Charleston, WV, letter to Frederick D. Isler, assistant staff director for Civil Rights Evaluation, USCCR, Feb. 17, 1999 (re: information for health care project), p. 1.

[629] John R. Lumpkin, director of Public Health, Illinois Department of Public Health, Springfield, IL, letter to Frederick D. Isler, assistant staff director for Civil Rights Evaluation, U.S. Commission of Civil Rights, February 1999 (re: information for health care project), enclosure, tab 2 (hereafter cited as Lumpkin letter).

[630] Jones letter, p. 1.

[631] Ibid.

[632] Ibid., p. 2.

[633] Mary C. Selecky, Secretary, State of Washington Department of Health, Olympia, WA, letter to Frederick D. Isler, assistant staff director for Civil Rights Evaluation, USCCR, Apr. 2, 1999 (re: information for health care project), p. 1 (hereafter cited as Selecky letter).

of Color.[634] The purpose of this report was to provide statistics on the health conditions of minorities in the State, analyze the data so that their health concerns could be addressed adequately, and serve as a "springboard" for improving data collection and analysis efforts in the area of health care for these groups and, in particular, some of the Hispanic and Asian American/Pacific Islander subgroups.[635] In July 1997, the department released a report on the State's plan for American Indian health care delivery.[636] This report found that American Indians have limited health care resources and difficulty accessing available services. The report presented 20 recommendations for improving American Indian health care in Washington State. The recommendations cover such issues as State-supported funding for improving health care, American Indian involvement in policy and program development, and technical assistance to the American Indian community on the State's health care system.[637]

In conjunction with the nationwide Healthy People 2000 and Healthy People 2010 initiatives instituted by HHS, many States have established similar programs, focusing on narrowing the disparities in health status of minorities. For instance, the Nebraska Department of Health, Office of Minority Health and Human Services, produced a report on the health of the State's racial and ethnic minorities.[638] The issues addressed in the report include access to care, health status, and risk factor prevalence for African Americans, Native Americans, Asian Americans, and Hispanics. The report targets issues specific to each group to be addressed in the Nebraska Year 2000 initiative. In addition, the report addresses issues of concern for women, broken down by racial and ethnic group, to identify how particular health concerns affect women of color differently.[639]

The Texas Department of Health has two reports stemming from the Healthy People 2000 initiative that look at health status by race and ethnicity[640] and by gender.[641] The report on race and ethnicity provides data about the status of Texas' predominant racial and ethnic populations in attaining the Healthy People 2000 goals and targets 18 health status indicators. The health status of racial and ethnic populations are particularly important in Texas because it has the third largest black population and the second largest Hispanic population among all States.[642] The gender report addresses 16 of the health status indicators.[643]

The State of Utah Department of Health has produced several categorical reports on minority and women's health issues.[644] In 1993 the department released a report on health status indicators by race and ethnicity.[645] This report includes indicators such as mortality rates, causes of death, and socioeconomic factors. While not considered a comprehensive data analysis of all health problems, the authors think that the report does provide a description of the relationship between racial/ethnic health factors in Utah as compared with national rates.[646] In 1996 the Utah Department of Health released a report prepared by the department and the State's Ad

[634] Washington State Department of Health, Center for Health Statistics, *Washington State Health Data Report on People of Color*, October 1992.

[635] Ibid., p. 1.

[636] Washington State Department of Health, Office of Community and Rural Health, *American Indian Health Care Delivery Plan*, July 1997.

[637] Ibid., pp. 4–5.

[638] Nebraska Department of Health, Office of Minority Health, *Nebraska's Racial and Ethnic Minorities and Their Health*, September 1996.

[639] Ibid.

[640] Texas Department of Health, Bureau of State Health Data and Policy Analysis, *Texas Healthy People 2000: Health Status Indicators by Race and Ethnicity, 1980–1996*, July 1998 (hereafter cited as Texas Department of Health, *Health Status by Race and Ethnicity*).

[641] Texas Department of Health, Bureau of State Health Data and Policy Analysis, *Texas Healthy People 2000: Health Status Indicators by Gender, 1980–1996*, October 1998 (hereafter cited as Texas Department of Health, *Health Status by Gender*).

[642] Texas Department of Health, *Health Status by Race and Ethnicity*, p. 1.

[643] Texas Department of Health, *Health Status by Gender*, p. 1.

[644] Rod L. Betit, executive director, State of Utah Department of Health, letter to Frederick D. Isler, assistant staff director for Civil Rights Evaluation, USCCR, Mar. 19, 1999 (re: information for health care project), p. 7.

[645] Utah Department of Health, Office of Surveillance and Analysis, Division of Community Health Services, *Utah's Healthy People 2000 Health Status Indicators by Race and Ethnicity*, May 1993.

[646] Ibid., pp. v–vi.

Hoc Women's Health Committee. The report shows the differences of health status, health-related behavior, and access to health care and utilization of health care services for men and women in Utah. The report is intended to inform those who make social and health policies of these differences, and how these differences and concerns should be addressed in future State policies.[647]

The Utah Department of Health also released a report in 1997 on maternal and infant health that provides information on the health and well-being of women of childbearing age in Utah.[648] In 1997 the University of Utah's Department of Health Promotion and Education prepared a report on the health status of ethnic populations for the Utah Department of Health.[649] The purpose of the report was to enhance the understanding of health issues that are important to Utah's racial and ethnic populations, and inform the Department of Health of the methods to collect ethnic health-related information in Utah.[650]

Most recently, the Utah Department of Health released its draft study on the health status of Utah residents by race and ethnicity.[651] Mainly a presentation of data from a variety of sources, it examines indicators such as the leading causes of death of American Indians, Asian Americans and Pacific Islanders, African Americans, Hispanics and whites, by age and sex, health risk factors, and life expectancy from birth.[652] The department expects to provide information on health care conditions of these communities, as well as to address and improve the health care services that they need and provide suggestions for responsive action.[653]

In 1993 the Rhode Island Department of Health released a report on the health of minorities in Rhode Island.[654] The report was intended to provide health indicators and patterns of health behavior and health care use in order to assess the health status of Rhode Island's minority populations.[655] The report is a foundation for a State plan aimed at addressing the health concerns of the minority groups in Rhode Island.[656] In 1995 the department released a "data sourcebook" that compares the minority and white populations in Rhode Island with respect to health status indicators and priority needs.[657]

Maine's Department of Human Services submitted to the Commission a report on women, as well as several outreach and education brochures for women and minorities prepared by various State agencies.[658] The 1998 report summarizes the findings of qualitative and quantitative data to assess health needs of women, which culminated in a State profile of women's health.[659] Selected issues discussed in the report include demographics, health status, behavioral health, health risks, and clinical preventive services relative to women.[660]

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647 Utah Department of Health, *Women's Health in Utah*, December 1996, p. vii.

648 *See* Utah Department of Health, Division of Community and Family Health Services, *Maternal and Infant Health*, September 1997.

649 *See* Utah Department of Health, Bureau of Surveillance and Analysis and Statewide Ethnic Health Committee, *Utah Health Status Survey on Ethnic Populations—Qualitative Component*, Final Report, November 1997 (hereafter cited as *UT Dept. of Health, Survey on Ethnic Populations*).

650 Ibid., p. 1.

651 *See* Utah Department of Health, Bureau of Surveillance and Analysis, Office of Pubic Health Data, *Health Status in Utah by Race and Ethnicity*, February 1999) (hereafter cited as *Health Status in Utah by Race and Ethnicity*).

652 Ibid., p. vii.

653 *UT Dept. of Health, Survey on Ethnic Populations*, p. 1.

654 Edward J. Martin, assistant director of Management Services, State of Rhode Island and Providence Plantations Department of Health, letter to Frederick D. Isler, assistant staff director for Civil Rights Evaluation, USCCR, Mar. 24, 1999 (re: information for health care project).

655 Rhode Island Department of Health, Office of Health Statistics, *The Health of Minorities in Rhode Island* (Providence, RI: Rhode Island Department of Health, May 1993) (hereafter cited as *The Health of Minorities in Rhode Island*).

656 Ibid.

657 Rhode Island Department of Health, Office of Health Statistics, *Healthy Rhode Islanders 2000 : Sourcebook for Minority Health Status*, May 1995, p. 2.

658 N. Warren Bartlett, director, Offices of Health Data and Program Management, State of Maine, Department of Human Services, letter to Frederick D. Isler, assistant staff director for Civil Rights Evaluation, USCCR, Mar. 18, 1999 (re: information for health care project).

659 Maine Department of Human Services, Bureau of Health, Division of Community and Family Health and Maine Department or Mental Health, Mental Retardation and Substance Abuse Services, *Women's Health: A Maine Profile*, 1998. Several Federal, public, and private organizations funded the project/report, including HHS's Region I Office on Women's Health.

660 *See* ibid.

In 1997 the Oklahoma State Department of Health released a comprehensive report on family planning services in the State that includes racial/ethnic data and statistics on women's needs with respect to this issue.[661] The department released a report on maternal and infant health data to address risk factors and characteristics of pregnant women and infants in Oklahoma County.[662]

The Office of Minority Health in the Virginia Department of Health, in conjunction with the State's Multicultural Task Force, produces an annual report on Virginia minority health data.[663] The 1997 report, which presents 1995 data, provides detailed health statistics for the racial and ethnic minority groups. Before 1997, health data were primarily aggregated as white and nonwhite, and did not distinguish information on the minority groups living in Virginia.[664] The expanded racial/ethnic breakdown in the report was developed in response to the Virginia Health Commissioner's Minority Health Advisory Committee's recommendation "to improve existing sources of data by adding more detail and refinement to include race/ethnicity, gender, age and local identifiers to Virginia vital health records and reports."[665] The objective of including expanded data on minorities is to provide an informative tool for Virginia's policymakers, health care providers, consumers, and the general public in the area of health care.[666] The State's Multicultural Health Task Force is currently doing a study to identify the contributors to the health status gap in Virginia and to develop strategies for future program planning.[667]

In 1993 Wisconsin's Department of Health and Social Services, Center for Health Statistics, issued a report on the health status of minority populations in Wisconsin.[668] The report examined health status at different life stages: birth and infancy, childhood and youth, young adulthood and middle age, and older age.[669] The findings were comprehensive. For example, for prenatal and infant health, the report found that in Wisconsin, women in ethnic and racial minorities were less likely to begin care in the first trimester of pregnancy and tended to make fewer prenatal visits, compared with statewide percentages. In 1991 black infants in Wisconsin were more likely to be born with low birthweight. Minority groups were also more highly represented among Wisconsin births to mothers less than 18 years old, among births to unmarried women, among births to women who have less than a high school education, among births that represent the mother's fourth or higher birth, and among mothers who had experienced another birth within the previous 24 months. Blacks and American Indians had higher than average infant mortality rates.[670]

The Delaware Health and Social Services Department submitted several reports to the Commission that covered health care issues affecting racial and ethnic minorities and women.[671] The Governor's Advisory Council is responsible for setting priorities to address problems and participating in efforts to improve minority health. The council also participates in programs that promote health and prevent disease in minority populations and identifies the effect that changes in the health care system will have on

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[661] Oklahoma State Department of Health, Maternal and Child Health Services, *Family Planning Services in Oklahoma*, 1997, p. xii.

[662] Oklahoma State Department of Health, Maternal and Child Health Planning and Evaluation, *Maternal and Infant Health in Oklahoma County*, no date.

[663] E. Anne Peterson, acting state health commissioner, Commonwealth of Virginia, Department of Health, Richmond, VA, letter to Frederick D. Isler, assistant staff director for Civil Rights Evaluation, USCCR, Apr. 13, 1999 (re: information for health care project) (hereafter cited as Peterson letter).

[664] Virginia Department of Health, Center for Health Statistics and Office of Minority Health, *Virginia Minority Health Data Report (City/County Tables) 1995*, 1997). In 1995 the population in Virginia was 6,550,826. Minorities were 25 percent of the total. African Americans (19.5 percent) were the largest minority group in Virginia, followed by Asian/Pacific Islanders (3.1 percent), and Hispanics (3.0 percent). Native Americans were less than 1 percent of the total population. Ibid., p. 1.

[665] Ibid.

[666] Ibid.

[667] Peterson letter, p. 1.

[668] Wisconsin Department of Health and Social Services, Division of Health, Center for Health Statistics, *Minority Health in Wisconsin: Toward a Healthy Diversity*, 1993.

[669] Ibid., p. xiii.

[670] Ibid., pp. xix–xx.

[671] Gregg C. Sylvester, Secretary, Delaware Health and Social Services, Office of the Secretary, letter to Frederick D. Isler, assistant staff director for Civil Rights Evaluation, USCCR, Apr. 12, 1999.

minorities.[672] In June 1998, the council released its progress report, which focuses on four target areas to be addressed to improve the health status of minorities in Delaware: infant mortality, cancer, HIV/AIDS, and health education.[673]

In conjunction with the reports produced on health status and health disparities, Delaware Health and Social Services has published much needed information on the racial/ethnic and gender composition of primary care physicians in the State. The report examines physicians practicing in five specialties: family practice, general practice, internal medicine, pediatrics, and obstetrics/gynecology. For minorities and women, the data show that in the entire physician database, 56 percent of the female physicians were in one of the primary care specialties. The smallest percentage of primary physicians was African Americans, even in the State's predominantly African American county. However, the highest proportion of Hispanic primary physicians (approximately 4 percent) practiced in the county with the highest number of Hispanic residents.[674] Identifying the demographic composition and practice patterns of health care providers is the necessary first step toward increasing minority and female representation in the medical profession.

In addition to the production of reports, State health departments have produced and disseminated other materials that address specific health issues. The Nebraska Health and Human Services System, in conjunction with HHS, prepared fact sheets on 17 issues related to women's health care. The fact sheets, covering such issues as access to health care, maternal and child health, cancer and other diseases, mammograms, and violence against women, were compiled for a women's health symposium held in May 1998.[675] In January 1999, the Nebraska Health and Human Services System's Office of Minority Health and Human Services presented a statistical document of minority health information. The statistics show that there is a "significant disparity in the overall health status and quality of life for racial/ethnic minorities in Nebraska."[676] Based on the statistics, the study reports that minorities in Nebraska are overrepresented in morbidity and mortality health rates and in disability rates.

Other data collection efforts have focused on disease-specific issues to generate an understanding of what factors lead to disparities in occurrence, treatment, and outcome. The Missouri Department of Health, for example, issued a report on the prevalence of diabetes among African Americans in various regions of the State.[677] National data show the disease to be more common and more severe among African Americans as compared with whites; the purpose of the Missouri study was to examine to what extent the trend exists in the State and to examine the health factors specific to the Missouri population of African Americans.[678] The same office recently produced a second report on the prevalence of activity limitation and arthritis among African Americans within specific geographic regions of the State.[679] Data show that African Americans rank arthritis as the top condition that limits major activities such as working, keeping house, and living independently.[680]

[672] Delaware Health and Social Services, *Report of the Governor's Advisory Council on Minority Health*, 1998, p. 4.

[673] Ibid. The report focuses on African Americans, although it acknowledges the increase in the Hispanic population by 60.9 percent since 1990. The council noted that the report is missing significant comment on the health status of Hispanics in the State and stated that the data provided for the report were mainly from the Delaware Vital Statistics Annual Report, which has limited coverage of the Hispanic population. According to the council's report, "Discussions are under way to broaden the scope of coverage of Hispanics in the near future." Ibid., pp. 2–3, 5–6.

[674] Ibid., pp. 6–7.

[675] Mike Johanns, Governor, State of Nebraska, letter to Frederick D. Isler, assistant staff director for Civil Rights Evaluation, USCCR, Feb. 16, 1997 (re: information for health care project), enclosure, "Fact Sheets on Women's Health for the Women's Health Symposium, May 14–15, 1998."

[676] Nebraska Health and Human Services System, Office of Minority Health and Human Services, *Minority Health Information*, January 1999, p. 10.

[677] Missouri Department of Health, Division of Chronic Disease Prevention and Health Promotion, Office of Surveillance, Research and Evaluation, *Prevalence of Diabetes Among African Americans in the City of St. Louis, Kansas City, and the Bootheel Region of Missouri*, October 1997.

[678] Ibid., p. 1.

[679] Missouri Department of Health, Division of Chronic Disease Prevention and Health Promotion, Office of Surveillance, Research and Evaluation, *Prevalence of Activity Limitation and Arthritis Among African Americans in the City of St. Louis, Kansas City and the Bootheel Region of Missouri*, January 1999.

[680] Ibid., p. 3.

These reports and findings illustrate quite plainly that disparities in health status and health care exist. Recognition by State health agencies that disparities are unacceptable is a first step. The volumes of information must now be analyzed further to include practical solutions for eliminating differences, which can be partially accomplished through improved access to care.

Increasing Access to Health Services

As demonstrated earlier in this report, one of the greatest predictors of poor health status is lack of access to health care.[681] Reconciling need with use has presented a dilemma for health care providers, particularly in predominantly minority communities. To remedy this, at least in part, some States have designed health service programs aimed specifically at those populations whose health needs most often go unmet.

For example, minority and poor women often receive relatively little prenatal care.[682] To address this, the Texas Department of Health established a prenatal program called Baby Bundles. The program recruits community volunteers to work with public health professionals in reducing the number of low-birthweight babies and lowering the infant mortality rate. Health clinics distribute baby clothing made by the volunteers to clinic mothers and children as an incentive to establish healthy practices, such as attending prenatal care visits, breast feeding, or completing all first-year well-baby checkups and immunizations.[683]

The Oregon State Health Division has a number of activities aimed at increasing health care participation among minorities and women. To address the high rate of infant mortality among African Americans, the State has developed an African American Infant Mortality Prevention Coalition. The State Health Division provides the coalition technical assistance.[684] The division also has two grants: a Federal Healthy Start grant to develop a community-based strategy to prevent and reduce infant mortality and the African American Birth Outcomes Project to develop an intervention model to prevent infant mortality.[685] These programs are intended to provide better access to medical care for mothers, including home visits by nurses, social and community support, and improved prenatal nutrition to reduce infant mortality and morbidity.[686] The Office of Community Services in the Oregon Health Division also has a preventive health and health services block grant for a program targeted to women of color who are the victims of domestic and sexual violence.[687] For HIV/AIDS prevention, the Oregon Health Division has established a partnership with the Multicultural HIV/AIDS Alliance of Oregon, a statewide grassroots organization advocating competent, culturally appropriate HIV prevention and service delivery. The partnership has produced the People of Color Needs Assessment, which has surveyed African American and Hispanic Oregonians about factors that have contributed to an elevated risk for HIV infection.[688]

Immigrants and refugees are among the most difficult to reach for health care. A few States administer programs to provide health care specifically for these populations. The Idaho Department of Health and Welfare has established the Migrant and Seasonal Farm Worker Outreach Project to meet the needs of the estimated 119,000 migrant and seasonal farmworkers in Idaho. The program uses the services of the Idaho Primary Care Association, an organization

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[681] *See* chaps. 2–3.

[682] *See* chaps. 2–3.

[683] Charles W. Pankey, director, Office of Equal Opportunity, Texas Department of Health, Austin, TX, letter to Frederick D. Isler, assistant staff director for Civil Rights Evaluation, USCCR, Feb. 19, 1999 (re: information for health care project), enclosure, Texas Volunteer Health Corps, "Baby Bundles."

[684] Elli Hall, Health Division, Oregon Department of Human Resources, memorandum to Mark Gibson, Governor's Office, Aug. 7, 1998 (re: data and public health programs for multicultural populations), p. 1 (hereafter cited as Hall memorandum).

[685] Ibid. *See also* Gary K. Weeks, director, Department of Human Resources, State of Oregon, letter to Frederick D. Isler, assistant staff director for Civil Rights Evaluation, USCCR, Mar. 12, 1999 (re: information for health care project) (hereafter cited as Weeks letter), enclosure, Oregon Health Division, Center for Child and Family Health, "Information for Governor's Task Force on Multi-Cultural Health," p. 1.

[686] Weeks letter, enclosure, Oregon Health Division, "Information on Multi-Cultural Health," p. 1. The Oregon Health Division reported its efforts and activities to prevent and reduce racial disparities in infant mortality rates to an African American Legislative Roundtable in 1997.

[687] Ibid.

[688] Hall memorandum, p. 5.

of nonprofit health centers offering preventive and primary health care services to medically underserved areas of the State. Although the Community and Migrant Health Centers deliver health care services to these populations, the State recognizes that there are still gaps in access to primary health services due to the population's frequent travel, isolated housing, social and cultural differences, and transportation difficulties. The outreach project, therefore, includes activities to reduce these barriers to care, assist in recruiting clients, provide health promotion and education, and facilitate health services and coordinated care through referral and followup. Areas covered under the grant include family planning, diabetes education, STD/HIV education and counseling, breast and cervical cancer education, and tuberculosis screening.[689] Outreach workers provide bilingual and culturally sensitive education services to groups and individuals.

Through the Illinois Department of Public Health's Center for Minority Health Services, a Refugee and Immigrant Health Screening Program coordinates the provision of health screening to Illinois refugees and Orderly Departure Program immigrants through identification, treatment, and followup of observed health problems.[690] As the first refugee health program in the United States to provide trained bilingual translators in its clinics, the Illinois program has been successful in contacting and screening more than 95 percent of new arrivals.[691] In Oregon another initiative focuses specifically on the health of immigrant children. The migrant immunization program immunizes preschool children in migrant communities to reduce the prevalence of vaccine-preventable disease.[692]

In Florida many of the initiatives targeting minorities and women focus on promoting treatment for HIV/AIDS patients. To ensure effective allocation of resources in the field, a Peer Advisory Review Workgroup for the Title II Ryan White Comprehensive AIDS Resources Emergency Act of 1990[693] was established. Under title II of the act, direct assistance is provided to Florida to improve the quality, availability and organization of health care and support services for individuals living with HIV and their families. Of particular concern to the workgroup is the lack of participation in the services and in the consortium by minorities, particularly African Americans. The absence of African American participation is critical, considering it has fallen short in proportion to the population affected by the disease.[694]

The workgroup has cited many possible reasons for this lack of participation among African Americans, including perceptions that their participation will not result in increased access, perceptions that their opinions will not be taken seriously in the decisionmaking process, cultural discomfort with the ways in which the consortium operates, not feeling welcomed, and prejudice. One remedy at the local level has been the establishment of an African American caucus whose input is then channeled into the consortium. The workgroup advised local constituents to address the issues of minority access and participation, but also acknowledged that a statewide workgroup needs to address this issue in a methodical manner and devise several approaches to share with consortia. The recommendation was a statewide Workgroup on Full Participation/Full Access to assess and remedy the obstacles to care.[695]

A separate program was designed in Florida to address HIV/AIDS in women. Under the Targeted Outreach to Pregnant Women Act of 1998,[696] five counties received funds to establish outreach programs to find pregnant women who are not receiving proper prenatal care and are at risk of delivering newborns who are exposed to HIV or are at risk of being affected by the mother's substance abuse. The outreach will in-

[689] Janie Aguilar, Idaho Department of Health and Welfare, Boise, ID, letter to Mireille Zieseniss, USCCR, Apr. 7, 1999 (re: information for health care project), enclosure, p. 10.

[690] Orderly Departure Program immigrants are defined as Vietnamese nationals who have legally applied for migration to the U.S.

[691] Lumpkin letter, enclosure, tab 2.

[692] Weeks letter, enclosure, Oregon Health Division, "Information on Multi-Cultural Health," p. 1.

[693] Pub. L. No. 101–381, sec. 201, §§ 2611–2620, 104 Stat. 586 (codified at 42 U.S.C. §§ 300ff-21–300ff-30 (1994 & Supp. II 1996).

[694] Florida Department of Health, Bureau of HIV/AIDS, "Serving Persons Living With HIV Disease, A Peer Advisory Review Interim Report," Aug. 15, 1998, p. 29 (hereafter cited as Florida Department of Health, "Serving Persons Living With HIV Disease").

[695] Ibid., pp. 31–32.

[696] FLA. STAT. 381.0045, ch. 381, title XXIX (1998).

volve locating these hard to find women and linking them with services.[697]

Improving Education and Outreach

Education and outreach programs serve not only to inform minority groups of their health care needs and options, but also to include minorities and women as active participants in health care. For outreach efforts to be effective, and for health providers to better serve consumers, the traditionally underserved must be involved in decisionmaking processes and be given the opportunity to voice their health concerns. For example, from 1996 to 1998, the Rhode Island Department of Health's Office of Minority Health and its Minority Health Advisory Committee sponsored a series of community forums targeting each of the major racial and ethnic minority groups for the purpose of providing consumers with an opportunity to express their concerns and needs regarding health care.[698] Eight community forums were held focusing on priority areas and barriers relating to health care for members of these groups. In 1998 the department released a report on the community forums, which would culminate in a minority health plan for the State.[699]

The Washington State Department of Health has established collaborative efforts with different American Indian tribes to address public health issues and implement programs.[700] In 1994 the department funded the first American Indian Tribal Leaders Summit on Health Reform. According to the Washington State Department of Health, one of the significant results was the establishment of the American Indian Health Commission for Washington State.[701] The commission is a consortium of federally recognized tribes, urban Indian health programs, and American Indian individuals.[702] Other outreach activities include ongoing partnering between local health jurisdictions and minority community organizations in an effort to expand the reach of public health activities and to promote communitywide participation in health services.[703]

Washington's Department of Health also sponsors a breast and cervical cancer program that targets low-income women ages 40 to 64 who are uninsured or underinsured. The program includes public education, quality assurance, tracking, surveillance, evaluation, and service delivery components.[704] In addition to these efforts, Washington State has developed public health improvement strategies throughout the State.[705] For example, department initiatives have been put in place to address diseases and illnesses, such as diabetes and tuberculosis, that disproportionately affect minority communities.[706]

The Utah Department reported its participation in an annual national summit that is held to address American Indian health care issues and concerns. The fifth annual summit on Indian health care issues was held in 1998 in Salt Lake City. The summit included 106 attendees representing 14 States, 53 tribal and urban program representatives, representatives from the Federal Government including Health Care Financing Administration (HCFA) staff, and a representative from the White House's Office of Management and Budget. The summit's recommendations include a clarification of HCFA's role with respect to services for American Indians, and a partnership of HCFA, other government agencies, and tribes to address the provision of health care.[707]

The Missouri Department of Health has taken a disease-specific approach to minority health care through the development of the department's Section of STD/HIV/AIDS Prevention and Care Services. The program addresses the importance of being responsive to the health care needs of specific populations at risk or di-

[697] Chris Kertesz, "Program Gears Up for Outreach to High-Risk Pregnant Women," *The Health Advisor*, Florida Department of Health, February 1999, p. 3.

[698] Rhode Island Department of Health, Office of Minority Health and the Community Resource Assessment Subcommittee, *Minority Health Advisory Committee Community Forum Report, Strategic Plan Series: Report I*, April 1998, executive summary, pp. 1–3.

[699] Ibid.

[700] Selecky letter, enclosure, "Washington State Department of Health, Current Health Care Initiatives," p. 2.

[701] Ibid., p. 3.

[702] Ibid., p. 2.

[703] Ibid.

[704] Ibid., p. 1.

[705] Ibid., p. 3.

[706] Ibid., pp. 3–5.

[707] Betit letter, enclosure, "Indian Health Care," p. 1.

agnosed with HIV and other STDs (sexually transmitted diseases), particularly the disproportionately affected women and minority populations. The section has placed a strong emphasis on prevention and care services targeting these women and minorities and it developed specific initiatives to address urban minority populations as well as those in rural communities.

The Texas Department of Health also has a breast and cervical cancer control program.[708] Its priority is African American women, who have the highest breast and cervical cancer mortality rates.[709] Unfortunately, the percentage of African American women enrolled in the program decreased after the first year, and the department concluded that specialized outreach may be necessary.[710] A 13-member work group met in February 1997 to address concerns about breast cancer screening among African American women to develop responses to the problems, and to develop links to other health systems to improve breast health care among African American women.[711] The group convened task forces on the topic in March 1997 and September 1998.[712] The department requested funding and recently received a cooperative agreement from the Centers for Disease Control and Prevention to pilot test outreach activities and screen African American women for breast and cervical cancer.[713]

In Texas technical assistance is available to health care providers in an effort to make health services more accessible to the Hispanic community. A manual was produced that explains how to determine bilingual staffing needs and discusses alternative methods for serving limited-English-proficient clients. It also provides information on volunteer interpreter services, and lists some of the cultural differences (for example, body language) of various Hispanic groups, so that health care providers can provide more culturally competent care.[714] Another manual describes the Texas Department of Human Services' Volunteer Interpreter Services Program and provides instructions for volunteer interpreters as well as for staff relying upon interpreters.[715]

Initiatives and Programs at Teaching Hospitals and Medical Schools

Many innovative programs being implemented at the local level, if adopted more universally, have the potential to vastly improve both health care delivery and the health status of underserved populations. The challenge of inclusive health care at the local level can be viewed in three areas: the development of diversity programs for health care providers in an effort to establish an understanding of what it means to provide culturally competent health care; assessment of community-specific health care needs, particularly for those within a designated service delivery area; and finally, the development of targeted programs that improve the access and quality of care for the underserved.

Public and private medical schools and teaching hospitals across the country are engaging in programs designed to identify problems with and work toward solutions for the health care system. The initiatives mentioned here are only a handful of those that have been

[708] Margaret C. Mendez, director, Breast and Cervical Cancer Control Program, Texas Department of Health, Austin, TX, memorandum to Bureau of Disease and Injury Prevention, Feb. 15, 1999 (re: materials related to access to health care) (hereafter cited as Mendez memorandum).

[709] Texas Department of Health, Breast and Cervical Cancer Control Program, "Progress Report, Breast and Cervical Cancer Control Program," Jan. 20, 1997, p. 2.

[710] Mendez memorandum, p. 2.

[711] Ibid, p. 1; *see also* Texas Department of Health, Breast and Cervical Cancer Control Program, "Workgroup Appointed to Address Breast Cancer Among African American Women," *Commitment*, vol. 6, no. 3 (March 1997), p. 4.

[712] Mendez memorandum, enclosure, "Task Force on Breast Cancer Among African American Women, March 17, 1997," p. 1.

[713] Sidney Shelton, chief, Bureau of Financial Services, and Margaret C. Mendez, director, Breast and Cervical Cancer Control, Texas Department of Health, letter to Sharron P. Orum, grants management officer, Procurement and Grants Office, Centers for Disease Control and Prevention, HHS, Oct. 6, 1998 (re: Breast and Cervical Cancer Prevention and Early Detection Program); Mildred S. Garner, grants management officer, Procurement and Grants Office, Centers for Disease Control and Prevention, HHS, letter to Margaret Mendez, Chronic Disease Prevention Program, Texas Department of Health, Jan. 27, 1999 (re: Notice of Cooperative Agreement Award No. U57/CCU606729–07–1, 1997 National Breast and Cervical Cancer Early Detection Program).

[714] *See* Bob Compton and Lonzo Kerr, Civil Rights Department, Texas Department of Human Services, *Accessing Services by the Hispanic Community*, 1998, p. 1.

[715] Texas Department of Human Services, Region 3, Accessing Services by the Hispanic Community, Supplemental Information: Volunteer Interpreter Services Program, November 1995.

implemented, but they represent feasible strategies for assessing and addressing the needs of minorities and women.

Diversity Programs and Cultural Competence

Before providers can begin serving the communities in need inclusively, an atmosphere of sensitivity and awareness must be reached among those actually providing health services. Medical schools and health care facilities alike have begun incorporating diversity issues and cultural competency training in their curricula and modes of operation. The increasing diversity of this country's population means all health care providers need to recognize and adapt the ways in which they provide care.

Commentators have suggested that one of the major issues confronting medical educators is how medical schools can prepare students to redress the maldistribution of physicians.[716] At the University of New Mexico an innovative program educates medical students on the specific needs of rural minority populations and at the same time provides health care to these underserved groups.[717] The Community Based Education Research and Treatment Program moves academic medicine out of the university hospital-clinic setting and into the rural or underserved community. The medical school curriculum at the University of New Mexico includes the conventional aspects of medicine, but training occurs in a community context that requires medical professionals to be culturally competent.[718]

Other schools of medicine have incorporated diversity issues and cultural competency training into the required coursework for medical students:

- At the Ohio State University College of Medicine and Public Health, a diversity module is part of the first year curriculum for all medical students. It includes cultural diversity, women's health, spirituality, and complementary medicine and therapies. In addition, a separate module on violence in society that addresses violence and rape against women is offered.[719]
- At the University of Nebraska College of Medicine the curriculum addresses issues of access, race, gender, equity, and allocation of resources. Students are required to take sessions in areas including language, culture and ethnicity in health care, gay and lesbian issues in health care, economics, justice and the allocation of health care resources, and Native American health care.[720]
- At the University of Southern California Department of Nursing, the Hispanic Initiative Program allows for the integration of conversational Spanish in the nursing curriculum. Students also learn about the diverse Latino culture, and about the health care needs of the large Latino population in the area. Latino bilingual nursing students serve as mentors to the non-Spanish-speaking students.[721]
- At the University of Pennsylvania School of Medicine, components dealing with cultural competency will be introduced into the year 2000 curriculum. A core of training called "humanism and professionalism" has been integrated into the medical school program and spans the entire 4 years of the curriculum. The purpose of the training is "to promote the appreciation of cultural differences and their influences in the physician-patient relationship, in the interface with the healthcare system, and in beliefs about health and disease." Methods include symposia, longitudinal learning experiences, and small group work

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716 Arthur Kaufman, Diane Klepper, S. Scott Obenshain, J. Dayton Voorhees, William Galey, Stewart Duban, Maggi Moore-West, Rebecca Jackson, Max Bennet, and Robert Waterman, "Undergraduate Medical Education for Primary Care: A Case Study in New Mexico," *Southern Medical Journal*, vol. 72, no. 9 (September 1982), pp. 1110–17.

717 Paul B. Roth, Dean, associate vice president for Clinical Affairs, Health Sciences, University of New Mexico School of Medicine, Albuquerque, NM, letter to Mireille Zieseniss, USCCR, Mar. 19, 1999 (re: information for health care project), enclosure, p. 1.

718 Ibid., p.1.

719 Robert L. Holder, associate to the vice president for Health Sciences, The Ohio State University Health Sciences Center, Columbus, OH, letter to Mireille Zieseniss, USCCR, Mar. 18, 1999 (re: information for health care project), enclosure, p. 1 (hereafter cited as Ohio State University Health Sciences Center response to information request).

720 Harold M. Maurer, chancellor, University of Nebraska Medical Center, Omaha, NE, letter to Frederick D. Isler, assistant staff director for Civil Rights Evaluation, USCCR, Feb. 26, 1999 (re: information for health care project), app. IB.

721 Linda Nola, director, Equity and Diversity, University of Southern California, Los Angeles, CA, letter to Mireille Zieseniss, USCCR, Mar. 15, 1999 (re: information for health care project), enclosure, p. 9.

with representation from various racial/ethnic groups.[722]

Fairview University Medical Center in Minneapolis, partner of the University of Minnesota's Academic Health Center, illustrates recognition of the need for integration of diversity awareness in the delivery of health care services in a practical setting. Because of the increasing diversity of the patient community and the change in racial makeup of health care providers, the Transcultural Care and Service Team was created in 1998. The Transcultural Care and Service Team has created subunits to address five elements: building the business case, developing a learning plan, developing a human resource plan, removing barriers to care and service, and recognizing and affirming diversity. Proposed plans for implementation include systems to educate staff about diversity and cultural differences; integration of diversity into normal business routines such as employee orientation, training, and education programs; and providing staff with the ability to recognize instances of prejudice and discrimination.[723] Although hospital administrators acknowledge that Fairview may be behind other institutions in terms of actually implementing diversity programs,[724] they have made strides toward reaching that goal and a commitment to improving their cultural sensitivity.

At the Boston Medical Center a committee was formed to produce monthly forums to address the health care beliefs and practices of specific racial/ethnic groups. Seven ethnic groups have been targeted based on the number of patients seen at the center from each of the groups: African American; Bosnian, Serbian, and Croatian; Puerto Rican; Vietnamese; Haitian; Somali:, and Cape Verdean.[725] The goal of the program is to educate staff on the appropriate methods of questioning patients about their culture, language, social customs, religious belief, taboos, family structure and roles, health care beliefs and living conditions as related to the individual's health needs.[726] The Boston Medical Center model demonstrates a direct response to an identified need; this is another effective strategy toward inclusive health care.

Similarly, the University of Washington School of Medicine combines American Indian traditional healing methods and modern medical practices in classroom and clinical experiences.[727] The School of Medicine also prepares American Indian students and physicians for academic careers by offering fellowships to support research and placing students in clerkships with rural and urban health care providers.[728]

Other programs focus on increasing the number of minority health care professionals by encouraging students in elementary, middle, and high schools to enter the health professions. For example, the Florida A&M University College of Pharmacy and Pharmaceutical Sciences promotes career opportunities through its Center for Excellence. The center matches high school students with African American students in the university's pharmacy program. In addition, students and faculty in the program jointly conduct research on pharmacy in the African American community.[729] Similarly, the University of California at San Diego works with middle and high school students in the community to increase the number of Hispanic students and faculty in its school of medicine.[730]

Another example of partnerships between schools and communities is the University of Arizona's American Indian Students United for Nursing (ASUN) Project, which works with students to encourage them to undertake careers in nursing.[731] Faculty members work with the uni-

722 Bernett L. Johnson, Jr., senior associate dean for Veterans Affairs, associate dean for GME and Minority Affairs, associate dean for Community Affairs, University of Pennsylvania Health System, letter to Frederick D. Isler, assistant staff director for Civil Rights Evaluation, USCCR, Apr. 12, 1999 (re: information for health care project), pp. 2–3 (hereafter cited as University of Pennsylvania Health System response to information request).

723 David R. Page, president/CEO, Fairview Health Systems, Minneapolis, MN, letter to Frederick D. Isler, assistant staff director for Civil Rights Evaluation, USCCR, Mar. 12, 1999 (re: information for health care project), tab 3.

724 Ibid., tab 4.

725 Boston Medical Center, *Catalog of Diversity Programs*, November 1998, p. 11 (hereafter cited as BMC, *Catalog of Diversity Programs*).

726 Ibid., p. 11.

727 Fox, "HRSA Opens Doors," p. 3.

728 Ibid.

729 Ibid.

730 Ibid.

731 Michelle Meadows, "Project Brings More Indians to Nursing," *Closing the Gap*, May/June 1999, p. 11.

versity's American Indian Institute to expose students to careers in nursing, and the faculty members participate in career days on reservations. ASUN also hosts monthly social and academic meetings with prenursing students and conducts blessing ceremonies before exam periods. In addition, ASUN has an Adopt-a-Tribe program through which the school establishes relationships with local communities and tribes.[732]

Assessing Community Needs

Health care initiatives extending beyond traditional medical care are necessary to address the needs of various communities. However, before programs can be implemented, it is necessary to assess what those needs are and identify community-specific deficiencies in existing health care systems. This is exactly what was done by the Archbishop's Commission on Community Health (ACCH) in St. Louis, Missouri. In an attempt to assess the needs of the communities served by facilities participating in the ACCH, the assessment process was aimed at identifying the gaps between the communities' resources and deficits, and to identify additional potential resources within the communities.[733] The assessment used both quantitative data in the form of census information to identify socioeconomic need, as well as other social indicators, and qualitative data gathered through interviews with community leaders and focus groups with the targeted members. The assessment identified several populations in which these gaps existed, among them immigrants. The health care needs of the immigrant communities included language assistance, transportation, and primary health care such as immunizations, baby care, and general hygiene education.[734]

Assessing the needs of a specific community in this way allows for development of a blueprint for programs to remedy the deficiencies, and is a necessary strategy if initiatives at the community level are to be successful. The Greenville Hospital System in Greenville, South Carolina, conducted a similar study that aimed to identify health issues of particular concern to Hispanics in the area.[735] After conducting surveys and holding discussions with focus groups and health care providers, the researchers were able to produce several recommendations for how to best approach the needs of the growing Hispanic community. Researchers inquired into the health care use patterns, barriers to care, and preferences for health care delivery of Hispanics in the area. They then assessed the views of current providers and their capacity to identify shortfalls. Recommendations included increasing the cultural competency of health care providers and patients so that each has accurate expectations of the other, focusing on community-based facilities with hours and payment options appropriate for low-income workers, recruiting Spanish speaking staff and improving communication abilities of existing staff, and using grassroots methods to reach the Hispanic community.[736]

Researchers from Georgetown University in Washington, D.C., in conjunction with members from local organizations and advocacy groups, recently completed a pilot study to identify the barriers faced by Latino immigrants in accessing health and social services.[737] Researchers held focus groups with Latino immigrants from different geographic regions in the city, and were specifically concerned with the respondents' familiarity with Latino agencies, what kinds of services they relied on for assistance, and where they experienced difficulty accessing services. They further identified deficiencies in health services, such as lack of bilingual providers, dearth of facilities in their areas of residence, and lack of available health insurance for immigrants. Recommendations for resolving these issues included creating outreach programs, fos-

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[732] Ibid.

[733] Sandy Kimball, employee relations coordinator, St. John's Mercy Medical Center, St. Louis, MO, letter to Mireille Zieseniss, USCCR, Mar. 31, 1999 (re: information for health care project), enclosure, "Archbishop's Commission on Community Health: Community Health Assessment, May 1996," p. 2.

[734] Ibid., p. 4.

[735] Frederick D. Hobby, vice president, Diversity and Service Excellence, Greenville Hospital System, Greenville, SC, letter to Frederick D. Isler, assistant staff director for Civil Rights Evaluation, USCCR, Mar. 24, 1999 (re: information for health care project), enclosure, p. 1. The project was funded by the Duke Endowment through its Immigrant Health Planning Grants program.

[736] Ibid., enclosure, pp. 13–14.

[737] Maria da Gloria Miotto Wright, coordinator, International Health Program, and Patricia A. O'Hare, associate professor of Nursing, Georgetown University, Washington, DC, letter to Mireille Zieseniss, USCCR, Apr. 26, 1999 (re: information for health care project).

tering collaboration among Latino agencies, and developing a Latino network of health and social services.[738] If widely publicized and presented to local health agencies, such studies have the potential to illustrate the need for community-specific program development and can influence policymaking.

There are many other examples of local research and community-based planning projects designed to highlight the concerns of specific populations. The Los Angeles County Department of Health Services director, in conjunction with the University of Southern California, has developed an initiative called Community-Focused Service Area Planning that will collaborate with communities to identify and address health care needs by service area.[739] At Lutheran General Hospital in Park Ridge, Illinois, the Healthy Communities Initiative has worked in partnership with local communities to assess their specific needs to build new models of care.[740]

Delivery of Services and Outreach Efforts

The initiatives being implemented at the local level vary in scope, intent, and outcomes, but they share the common theme of integrating health services to address the needs of underserved populations and ultimately improve access to care. Through innovation, reassessment of funds, and creative use of available resources, many of these sample initiatives and programs can be replicated, resulting in a broader impact.

Perhaps one of the most innovative and effective uses of resources is the University of Mississippi Medical Center's Medical Mall. This initiative's goal is to improve access to care for the medically underserved in the Jackson, Mississippi, area. A deserted shopping mall was converted into the Jackson Medical Mall with the University of Mississippi Medical Center as the anchor tenant.[741] The facility provides preventive, primary, and a full range of specialty care, including obstetrics-gynecology and pediatrics. The Mississippi Department of Health has also established clinics in the mall for prenatal care, immunizations, and sexually transmitted diseases.[742]

The mall serves as a one-stop location for comprehensive medical needs. In addition to the clinics and medical facilities, spaces are leased to retail businesses offering health care products such as home medical equipment. The mall provides physical and occupational therapy, including a mall concourse marked with mile markers for indoor walkers who walk for rehabilitation or fitness, and offers a free daycare center for patients who must bring their children with them. The 700-seat movie theater will undergo renovations to become a medical conference center, for both the community and health professionals. This year, it is expected that 150,000 individuals will seek care at the Medical Mall, most of whom are medically indigent or receive medicaid.[743] Area churches have also participated by providing transportation to the mall for patient appointments. The mall will also be headquarters for the Jackson Heart Study, the largest study of cardiovascular disease risk factors in African Americans ever undertaken by the National Institutes of Health.[744]

Targeting Specific Populations

Other initiatives target smaller, more segmented groups. The University of Arizona has developed several programs aimed at improving the health status of residents of rural areas, including poor Hispanic border populations and Indian tribal communities, and empowering them with the ability to coordinate services for themselves. The University of Arizona's Rural Health Office sponsors a mobile clinic program that provides primary care clinical services, health promotion and disease prevention educational programs, and technical assistance for

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738 Ibid., enclosure, p. 5.

739 Roberto Rodriguez, executive director, Los Angeles County/University of Southern California Medical Center and Northeast Cluster, Los Angeles, CA, letter to Frederick D. Isler, assistant staff director for Civil Rights Evaluation, USCCR, Mar. 8, 1999 (re: information for health care project), enclosure, p. 1.

740 Kenneth Rojek, chief executive, Lutheran General Hospital, Park Ridge, IL, letter to Frederick D. Isler, assistant staff director for Civil Rights Evaluation, USCCR, Mar. 18, 1999 (re: information for health care project), p. 2.

741 Wallace Conerly, vice chancellor for Health Affairs and Dean, School of Medicine, The University of Mississippi Medical Center, Jackson, MS, letter to Frederick D. Isler, assistant staff director for Civil Rights Evaluation, USCCR, Feb. 17, 1999 (re: information for health care project), p. 1.

742 Ibid., p. 3.

743 Ibid., p. 2.

744 Ibid., pp. 5–6.

community development in underserved communities in rural areas, many of which are heavily populated by American Indians and Hispanics. Community health advisors and other people who provide health education and outreach services serve as liaisons with the mobile clinic program.[745]

The Rural Health Office is also involved with the Tohono O'odham Indian Tribe to implement a professional education and training program for tribal members who will staff a 60-bed nursing home facility being constructed on a reservation. The tribe selected individuals to train for administrative staff positions.[746] In addition, in 1997 the Rural Health Office began working with the Hopi Tribe to develop a health career education program that is community based, demand driven, and focused on the tribe's goal of community development through on-reservation education programs.[747] Tribal members are being trained to staff a new Hopi ambulatory care facility. In 1998 Northern Arizona University received a grant from the Howard Hughes Medical Institute for science education, including support for teaching assistants and laboratory equipment to deliver health-related coursework to the Hopi Reservation high school via distance-learning technology.[748]

After assessing the needs of a local Japanese community, the University of Michigan Health System established the Japanese Health Clinic, an Internal Medicine Department-sponsored clinic staffed by bilingual providers who are knowledgeable about Japanese diet, culture, and traditional medicine.[749] As a result of the success of the Japanese program, the Women's Health Program is developing a women's health clinic designed to provide a culturally appropriate response to the needs of women from Muslim, Arab, Chaldean, and Middle Eastern countries.[750]

Because of the alarming increase in HIV infection among African Americans, the Cleveland Clinic in Cleveland, Ohio, has partnered with a nearby church to develop an effective outreach program for AIDS education, prevention, and early detection in the African American community.[751] The program, which is housed in the church and staffed by the Cleveland Clinic and volunteers from the congregation, includes a curriculum of educational events at weekly intervals, a place for HIV-infected individuals and their families to gather, an anonymous testing program, and counseling services.[752] Treatment for AIDS patients is available at the Cleveland Clinic, which is only a few blocks away.

At Southern Illinois University in Carbondale, Illinois, several projects have been developed that target health concerns of the immigrant and migrant worker populations. One project is the Immigrant and Migrant Battered Women Project in which staff from the Center for Rural Health and Social Service Development, the International Development Office, and the Women's Center in Carbondale have developed presentations and a video on spousal abuse in these communities. Another project has addressed rural health safety for Hispanic families, targeting migrant and seasonal farmworkers to improve their health and safety by reducing unintentional injuries. Materials are provided in English and Spanish.[753]

At the Oregon Health Sciences University (OHSU), multiple institutional initiatives address health care for women and minorities. In 1997 OHSU established a Center for Women's Health that integrates health care services and gender-related research and serves as a center to train future physicians, nurses, and dentists. The unique aspect of the center is that its focus is not limited to the traditional areas of women's health care, obstetrics/gynecology, but instead takes a more holistic approach by including nu-

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[745] University of Arizona, *Rural Health Office Progress Report, 1997–98*, p. 2.

[746] Ibid., p. 5.

[747] Ibid., p. 6.

[748] Ibid., p. 7.

[749] Gilbert S. Omenn, executive vice president for Medical Affairs, CEO, University of Michigan Health System, Ann Arbor, MI, letter to Frederick D. Isler, assistant staff director for Civil Rights Evaluation, USCCR, Mar. 15, 1999 (re: information for health care project), p. 2.

[750] Ibid., p. 2.

[751] John D. Clough, director of Health Affairs, the Cleveland Clinic Foundation, Cleveland, OH, letter to Frederick D. Isler, assistant staff director for Civil Rights Evaluation, USCCR, Mar. 25, 1999 (re: information for health care project), p. 2.

[752] Ibid., p. 2.

[753] Jo Ann E. Argersinger, chancellor, Southern Illinois University , Carbondale, IL, letter to Frederick D. Isler, assistant staff director for Civil Rights Evaluation, USCCR, Feb. 26, 1999 (re: information for health care project), enclosure, pp. 2–3.

trition and most medical specialties.[754] OHSU also has an Indochinese Psychiatric Clinic that provides specialized services to Southeast Asian refugees. Additionally, OHSU coordinates the Screening Kids Informing Parents Program, which sends faculty and students into community centers and schools where they provide free health care assessments to inner city children. The program, administered by the Child Development and Rehabilitation Center and the Portland metropolitan area public schools, is intended to teach parents how to become involved in their child's health care.[755]

As mentioned above, the Office on Women's Health in HHS' Office for Public Health and Science designates medical schools across the country as National Centers of Excellence in Women's Health for their demonstrated commitment to issues in women's health. The Ohio State University Health Sciences Center is one such center. The Women's Wellness Center was opened in which various programs are offered, including, among other offerings, a women's mood disorder clinic, osteoporosis prevention, contraceptive care clinic, and a menopause clinic. In addition, the Women's Wellness Center is home to the Ohio Women's Heart Program, an effort to increase women's awareness of cardiovascular disease risk factors. Ohio State also has a series of initiatives for improving community development in the health care arena. Included in this are the Asian Consumer Health and Wellness Initiatives and the Hispanic Consumer Health and Wellness Initiatives. Both initiatives seek to improve access to care for these communities and include the provision of services and materials in multiple languages.[756]

The University of Pennsylvania Health System has implemented several programs targeting underserved communities. One, the Community Collaborative, is part of an overarching initiative, FOCUS on the Health of Women.[757] The Community Collaborative addresses prevention, diagnosis, and treatment strategies for all women, with particular focus on vulnerable populations, such as minority women, women in poverty, and elderly women. FOCUS works collaboratively with community-based organizations to implement these activities. Another innovative program, Bridging the Gaps, is a multi-institutional effort that places medical students in underserved communities throughout the city.[758] Medical, nursing, dental, social work, and law students provide health and social services each summer. They then share the strategies and resources they have developed with local agencies, community leaders, public health officials, and university faculty.

Evanston Northwestern Healthcare in Evanston, Illinois, with funding from the Illinois Department of Public Health, Office of Women's Health, has developed the Community Wellness Initiative to improve outreach and access to health care.[759] One program in the initiative, called Heart to Heart: A Dialogue with My Sisters, is a 12-week educational program focusing on heart disease in African American women. The initiative also coordinates risk screening programs, including blood pressure, cholesterol, heart disease, and osteoporosis screenings in various locations throughout the community.[760]

University Hospital at the University of Utah has developed many initiatives to target the needs of minorities and women.[761] One program demonstrates a commitment to medically underserved teen parents. The Teen Mother

754 Timothy M. Goldfarb, director, Health Care System, Oregon Health Sciences University, Portland, OR, letter to Mireille Zieseniss, USCCR, Mar. 19, 1999 (re: information for health care project), enclosure, "The Campaign for Women's Health at Oregon Health Sciences University," p. 2.

755 Ibid., p. 2.

756 Ohio State University Health Sciences Center response to information request, enclosure, p. 1.

757 University of Pennsylvania Health System response to information request, enclosure, p. 1.

758 Ibid., attachment H. The University of Pennsylvania was designated as a Center of Excellence in Women's Health by the Office of Women's Health at HHS. This outreach effort is one of the activities implemented through the Center of Excellence.

759 William R. Luehrs, senior vice president, Human Resources, Evanston Northwestern Healthcare, letter to Frederick D. Isler, assistant staff director for Civil Rights Evaluation, USCCR, Apr. 26, 1999 (re: information for health care project), enclosure, p. 1.

760 Ibid., p. 2.

761 Jesse M. Soriano, director of Health Sciences, Office of Ethnic Minority Affairs, University of Utah, letter to Mireille Zieseniss, USCCR, May 19, 1999 (re: information for health care project).

and Child Program offers comprehensive health care for pregnant and parenting teens until they are 19 years old. The program provides prenatal services, postnatal care, pediatric care, family counseling, vocational counseling, and nutritional counseling, as well as support groups and services for teen fathers.[762] The hospital also provides other maternal health services, including reduced rate ultrasounds for uninsured patients who do not have access to subsidized prenatal care and car seats for those parents who cannot afford them.[763]

Assisting the Economically Disadvantaged

Financial constraints present an often insurmountable barrier to care, particularly for racial/ethnic minorities and women. Many teaching hospitals provide care for the "medically indigent" and uninsured populations, and in fact teaching hospitals serve a disproportionate number of individuals unable to pay.[764] As service providers and educational facilities, they have the responsibility to make services available to all patients in need, regardless of ability to pay. Programs have been designed to make the fulfillment of this responsibility a possibility. For example, at Ingham Regional Medical Center in Lansing, Michigan an access to care program was initiated to create an organized system of care for the indigent, uninsured, and underinsured.[765]

The goal of the project is to reach agreement between Ingham and Sparrow Health systems, the two area health care systems, and to plan a collaboratively funded and delivered organized system of care for the economically needy in the area. The two health systems are still reaching concurrence on the coverage options to be developed, funding designs, and delivery mechanisms. Network centers will be established to serve as neighborhood-based access points where barriers to personal health care access can be addressed. The network center will be a shared facility occupied by both neighborhood and agency representatives to help neighborhood residents increase access to health and human services,[766] as well as to improve their physical and social environment.

The children of uninsured parents make up a particularly vulnerable population whose health care needs often go unmet. The State University of New York Health Science Center at Syracuse cosponsors a program called Children's Health Place that is a free pediatric health clinic located in a low-cost government housing development that is home to a below poverty level population of African, Hispanic, and Asian Americans.[767] Started in 1992 in response to alarmingly high rates of infant mortality, low immunization rates, teen pregnancy, and sexually transmitted diseases, as well as overuse of hospital emergency rooms, the facility is staffed by volunteer physicians, nurses, and medical students. The program also has a 36-foot van equipped with examining rooms, a dental room, nursing station, immunization room, waiting room, and computers for electronic medical records.[768] In its 7 years of operation, Children's Health Place has made a significant contribution toward improving the health of children in its service area. Immunization rates are up to 90 percent, emergency room visits have been reduced by 40 percent, and in 1996–97 there were no reported cases of infant mortality among those being served by the facility.[769]

Increasing the Number of Minorities and Women in Research

Several initiatives are aimed at increasing the representation of women and minorities in research, both as subjects and as researchers. The Duke University Health System developed a Center for Minority Based Clinical Research

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[762] Ibid., attachment 9, p. 2.

[763] Ibid.

[764] *See* chap. 2.

[765] W. Lee Hladki, chief community benefits officer, Ingham Regional Medical Center, Lansing, MI, letter to Rebecca Kraus, USCCR, Mar. 4, 1999 (re: information for health care project), enclosure, p.3 (hereafter cited as Hlaki letter). Ingham Regional Medical Center is also affiliated with Michigan State University.

[766] Ibid., enclosure, p. 4.

[767] Kathy Walrod, Office of Personnel, General Administration, State University of New York Health Sciences Center, Syracuse, NY, letter to Mireille Zieseniss, USCCR, Mar. 16, 1999 (re: information for health care project), p. 2. This project is cosponsored by the Minority Health Office at SUNY–Albany and the Gifford Foundation.

[768] Ibid., p. 2.

[769] Kathy Walrod, Office of Personnel, General Administration, State University of New York Health Sciences Center, Syracuse, telephone interview, Apr. 7, 1999, p. 1.

to provide access to clinical trials to minority patients within the Duke health system as well as to provide training and career opportunities for minority investigators.[770] At the University of Louisville Health Sciences Center, funds are allocated each year for a research on women grant. The grant is available to full-and part-time faculty, and its primary purpose is to provide support to stimulate scholarship on women and encourage research on women's issues.[771]

[770] Vicki Y. Saito, assistant vice chancellor for Health Affairs, Duke University Medical Center, Durham, NC, letter to Mireille Zieseniss, USCCR, Apr. 1, 1999 (re: information for health care project), enclosure, "Concept Sheet: Center for Minority Based Clinical Research," p. 2.

[771] Mark P. Pfeifer, acting associate vice president for Health Affairs and acting vice dean for Clinical Affairs, University of Louisville Health Sciences Center, Louisville, KY, letter to Frederick D. Isler, assistant staff director for Civil Rights Evaluation, USCCR, Mar. 11, 1999 (re: information for health care project), p. 1.

Appendix 4.1

HHS Spending on Programs Targeted to Minority Health and Assistance (dollars in thousands)

HHS agency	FY 1998	FY 1999	FY 2000
HRSA	93,919	139,848	213,683
IHS	2,459,787	2,651,524	2,822,474
CDC	83,788	139,833	169,833
NIH	822,201	909,675	928,406
SAMHSA	5,785	33,986	34,404
AHCPR	8,975	19,000	29,600
AOA	0	0	3,068
OS/OPHS/OMH	29,034	28,000	28,000

SOURCE: U.S. Department of Health and Human Services, Novella Matthews, Office of Budget, Office of the Assistant Secretary of Management and Budget, fax to Eileen Rudert, Office of Civil Rights Evaluation, U.S. Commission on Civil Rights, no date (re: request for information), attachment, "Minority Health and Assistance: Direct/ Specifically Targeted Programs Only."

HHS Spending on Programs Targeted to Minority Health and Assistance as a Percentage of the Total HHS Budget

HHS agency	FY 1998	FY 1999	FY 2000
HRSA	.026	.036	.534
IHS	.684	.699	.705
CDC	.023	.037	.042
NIH	.229	.240	.232
SAMHSA	.002	.009	.009
AHCPR	.002	.005	.007
AOA	–	–	.000
OS/OPHS/OMH	.008	.007	.007

SOURCE: Calculated from figures from the U.S. Department of Health and Human Services, Novella Matthews, Office of Budget, Office of the Assistant Secretary of Management and Budget, fax to Eileen Rudert, Office of Civil Rights Evaluation, U.S. Commission on Civil Rights, no date (re: request for information), attachment, "Minority Health and Assistance: Direct/Specifically Targeted Programs Only." The total HHS budget in FY 1998 was $359.5 billion; the FY 1999 budget was $379.3 billion; the projected FY 2000 budget was $400.3 billion.

Appendix 4.2
HHS Spending on Programs Targeted to Women (dollars in thousands)

HHS agency	FY 1998	FY 1999	FY 2000
FDA	23,754	23,101	23,544
HRSA	1,044,792	1,139,836	1,187,074
IHS	119,298	123,460	129,460
CDC	550,748	628,146	671,244
NIH	2,085,891	2,340,685	2,404,437
SAMHSA	177,506	202,764	207,739
AHCPR	33,976	40,000	50,000
HCFA	44,132,675	46,038,300	48,881,483
ACF	87,840	90,000	103,500
AOA	357,140	357,140	382,660
OS/OPHS	31,908	36,299	29,576

SOURCE: U.S. Department of Health and Human Services, Novella Matthews, Office of Budget, Office of the Assistant Secretary of Management and Budget, fax to Eileen Rudert, Office of Civil Rights Evaluation, U.S. Commission on Civil Rights, no date (re: request for information), attachment, "HHS Women's Health."

HHS Spending on Programs Targeted to Women as a Percentage of the Total HHS Budget

HHS agency	FY 1998	FY 1999	FY 2000
FDA	.007	.006	.006
HRSA	.291	.301	.313
IHS	.033	.033	.034
CDC	.153	.166	.177
NIH	.580	.617	.607
SAMHSA	.047	.053	.055
AHCPR	.009	.011	.013
HCFA	12.275	12.138	12.889
ACF	.024	.024	.027
AOA	.099	.094	.100
OS/OPHS	.009	.010	.008

SOURCE: Calculated from figures from U.S. Department of Health and Human Services, Novella Matthews, Office of Budget, Office of the Assistant Secretary of Management and Budget, fax to Eileen Rudert, Office of Civil Rights Evaluation, U.S. Commission on Civil Rights, no date (re: request for information), attachment, "Minority Health and Assistance: Direct/ Specifically Targeted Programs Only." The total HHS budget in FY 1998 was $359.5 billion; the FY 1999 budget was $379.3 billion; the projected FY 2000 budget was $400.3 billion.

Chapter 5

Findings and Recommendations

Setting the Stage for Civil Rights in Health Care

Summary

Despite efforts to eliminate discrimination and reduce racial segregation over the past 30 years, there has been little change in the quality of or access to health care for many minorities and women. Discrimination in health care delivery, financing, and research continues to exist. Such discrimination is perpetuated in part by failure of Federal agencies to implement and vigorously enforce Federal civil rights laws in the health care context. As a result, policies and practices that result in disparate impact on minorities and women continue to thrive.

The Federal Government has made attempts to ensure equal access to health care through statutes such as the Hill Burton Act, title VI of the Civil Rights Act of 1964, and title IX of the Higher Education Amendments Act of 1972. These Federal civil rights statutes were enacted to fight discrimination on the basis of race, color, national origin, or sex, and if enforced vigorously, could have a positive effect on ensuring equal access to quality health care for women and minorities. However, the Department of Health and Human Services (HHS) has faced several deficiencies, including shortage of resources and funding, which have hampered its ability to enforce civil rights laws and ensure nondiscrimination in the health care context. The result is the perpetuation of severe disparities in health status and access to health care services between minorities and nonminorities and women and men.

Finding: Racial disparities in the quality of health care are related to differences in both need and access. For example, blacks in the United States are more likely to require health care services but are less likely to receive such services, including certain treatments and therapies, than are white persons. Racial disparities have been found in the likelihood of undergoing bypass surgery and in receiving a kidney transplant and other life-saving procedures.

Despite a focus on women's and minorities' health, HHS' Office for Civil Rights (OCR) generally has failed to enforce civil rights laws vigorously and appropriately. The failure of HHS/OCR to be proactively involved in health care issues or initiatives has resulted in the continuance of policies and practices that, in many instances, are either discriminatory or have a disparate impact on minorities and women. Further, although the Office of Minority Health and the Office of Women's Health within HHS' Office of Public Health and Science have been established to ensure that these issues are addressed throughout the Department, it appears that their input has been met with some resistance from the agencies within HHS that actually develop programs. Thus, there remain disparities in access to health care and in health care research, and unequal distribution of health care financing in the United States.

Health care disparities also are the result of discrimination, differences in access to quality health care, socioeconomic barriers, and cultural barriers. Health status is intimately linked to race, ethnicity, and gender. Programs that do not consider racial, ethnic, and gender variations in health, income, etc., run the risk of continuing or widening such disparities. The delivery of quality health care in the United States caters to the needs of selected segments of society. Racial discrimination and segregation are common and ingrained in health care in such a way that health care services and benefits are frequently not available to minorities and the poor. Thus, failure to recognize that differences in health care delivery, financing, and research are discriminatory barriers to health care translates

into and perpetuates differences in health status.[1]

Recommendation: For health care programs to be effective in reducing disparities and improving conditions for women and minorities, ultimately they must be implemented at the community level. It is imperative that HHS/OCR become actively involved in minority and women's health initiatives from conception and that minority and women's concerns become ingrained in the process of developing all HHS health care programs from the initial planning stages. The ultimate goal toward which HHS should strive is to no longer need a separate focus for women's health and minority health because that focus will be inextricably integrated into the fabric of every project, every grant, and every program from initial development.

However, new minority and women's programs and initiatives alone cannot improve the health of the Nation. To address issues related to unequal access to health care effectively, HHS must focus its attention on vigorous civil rights enforcement. OCR, as the civil rights enforcement office of the Federal agency responsible for the Nation's health, must be actively involved in eliminating health care practices that result in unequal access to and receipt of quality health care. Failure to do so results in an unstated acceptance of poor or nonexistent health care for minorities and women, and a perpetuation of inequality in the Nation's health care system.

Chapter 2: Disparities, Discrimination, and Diversity in Health Care

Summary

There are many examples of disparities in health status between racial/ethnic groups and between men and women: infant mortality rates are 2½ times higher for blacks, and 1½ times higher for American Indians, than for whites; the death rate for heart disease for blacks is higher than for whites; individuals from racial and ethnic minority groups account for more than 50 percent of all AIDS cases although they only account for 25 percent of the U.S. population; the prevalence of diabetes is 70 percent higher for blacks and twice as high for Hispanics as compared with whites; Asian Americans and Pacific Islanders have the highest rate of tuberculosis of any racial/ethnic group; cervical cancer is nearly five times more likely among Vietnamese American women than white women; women are less likely than men to receive life-saving drugs for heart attacks; more women than men require bypass surgery or suffer a heart attack after angioplasty.

In addition to recognizing the disparities in health status between white Americans and minority groups, it is vitally important to recognize differences within groups as well. Ethnic and racial minority communities are comprised of diverse groups with diverse histories, languages, cultures, religions, beliefs, and traditions. This diversity is reflected in the health care they receive and the experiences they have with the health care industry. Nonetheless, there has been relatively little research done on the differences in accessing quality health care by racial/ethnic subgroups, and few data are available on many of these groups. Similarly, the unique experiences of women of color have been largely ignored by the health care system. These women share many of the problems experienced by minority groups, in general, and women, as a whole. However, race discrimination and sex discrimination often intersect to magnify the difficulties minority women face in gaining equal access to quality health care.

These gaps in health status, and the absence of relevant health information, are directly related to access to health care which, in addition to being affected by race/ethnicity and gender, is affected by socioeconomic status. For example, racial and ethnic minorities tend to have lower levels of educational and occupational attainment and therefore less income than whites, resulting in disproportionate rates of poverty and the inability to obtain adequate health care financing. Education, occupation, and income, therefore, all play a role in determining the extent to which an individual will have adequate financial access to health care. Thus, women and racial/ethnic minorities who fare worse socioeconomically, also suffer inequities in access to and receipt of quality health care, and thus

[1] *See generally* chaps. 2–4. *See also* U.S. Commission on Civil Rights, *The Health Care Challenge: Acknowledging Disparity, Confronting Discrimination, and Ensuring Equality, Vol. II. The Role of Federal Civil Rights Enforcement Efforts,* September 1999 (hereafter cited as USCCR, *The Health Care Challenge,* vol. II), chaps. 1, 3, and 4.

health status. Nonetheless, several studies have shown that access to health care service delivery is associated with improved health outcomes.

Another critical element to the provision of quality health care for minorities is cultural competency. Nutritional deficiencies and dietary variations, genetic differences, and lifestyle habits all contribute to differences in health status. Without understanding and incorporating these differences, health care cannot be provided in a culturally competent manner. Culturally competent care is defined as care that is "sensitive to issues related to culture, race, gender, and sexual orientation." Cultural competency involves ensuring that all health care providers can function effectively in a culturally diverse setting; it involves understanding and respecting cultural differences. Linguistic barriers also affect the quality of health care services, particularly for Hispanics and Asian Americans.

Disparities in health status and access to care are further fueled by the structure of the health care industry in the United States, which is comprised of several components, including health care professionals, facilities, financing organizations, and research organizations. Currently, there are relatively few minorities and women involved in the system at influential levels and as health care practitioners. This is problematic for several reasons, but most importantly because the absence of women and minorities as health professionals limits the influence they can have on the restructuring of existing systems and the eventual improvement of health care delivery to all populations.

In addition to cultural awareness, the incorporation of women's and minorities' perspectives into the provision of health care will improve the quality of care these groups receive. Areas that are heavily populated by minorities tend to be medically underserved. A lack of minority doctors may result in limited access to health care for minorities, since minority health care providers are more likely to serve minority patients. Even when health care services are available, minorities may face racial discrimination that makes it difficult for them to obtain care or limits their choices among health care providers. Programs aimed at increasing the numbers of minorities enrolled in medical schools have had only marginal success.

Recognizing Diversity

Finding: Racial and ethnic minority communities differ on several socioeconomic indicators, including health status. In addition, cultural differences, such as traditional healing practices, religious beliefs, and language, have an effect on health status and access to quality health care. Although race and ethnicity are often divided into five categories (white, black, Asian American, Native American, and Hispanic), there is great diversity within those five groups.

For example, the African American community is quite diverse, including persons who have been in the United States for several centuries, persons of African and Caribbean decent, and more recent immigrants from countries such as Egypt, Ghana, Nigeria, Haiti, and Jamaica. Very little research has been done on health status differences among the subcultures in the African American community. Some studies have indicated differences in disease prevalence rates between American-born African Americans and more recent immigrants. Further, there are cultural differences within the African American community that could affect how certain African Americans seek and receive health care. Similarly, Asian American communities, Native American communities, and Hispanic communities are heterogeneous and experience health care in diverse ways.[2]

Recommendation: Federal, State, and local programs and initiatives addressing health care issues must take into consideration differences among and within racial and ethnic groups. In particular, health researchers and providers must address cultural differences within minority communities when examining racial differences in death rates, disease rates, and access to care delivery and financing. Further, researchers both within and outside the Federal Government should conduct community-specific and geographical studies to determine the health care issues that are specific to certain ethnic groups, and to various regions of the country (for example, minorities in rural areas as compared with those living in a metropolitan setting). Once these group-specific health concerns are cited, it will be necessary to further understand

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[2] *See* chap. 2, pp. 23–28. *See generally* chap. 2, "Profile of Five Communities," pp. 23–55.

the distinct patterns and behaviors that might lead to certain health outcomes.

In addition, health care practitioners must be cognizant and respectful of cultural differences and beliefs. Medical and health professional schools must include diversity and cultural competency courses as part of the required curriculum for students. Professional organizations, such as the American Medical Association and the American Dental Association, should provide seminars on diversity and cultural competence as well. These courses should address traditional, folk, and religious healing practices to the extent that such practices can be used in conjunction with prescribed medical treatments.

Finding: Compared with other racial/ethnic groups, Asian Americans and Pacific Islanders as a whole have relatively low rates of HIV/AIDS infection. These low rates may reflect a variety of factors, including differences in intravenous drug use and sexual behavior, but also the underreporting of infection. AIDS outreach workers suggest that AIDS is vastly underreported among Asian Americans, partly because of a reluctance to discuss the sensitive topics surrounding AIDS. The result is that many Asian Americans do not seek medical attention until very late stages of the disease. The low numbers have also reinforced the denial of many Asian Americans that AIDS is indeed a threat, and cultural sensitivities within the Asian American community may preclude discussion of high-risk behaviors associated with AIDS transmittal. Moreover, it has been speculated that because of the geographic and social isolation of many AAPI communities, the effect of HIV is magnified once it is introduced into the communities.

Experts agree that education about the transmission of HIV is particularly important in populations where incidence rates are low because people may erroneously perceive themselves not to be at risk. However, efforts to educate Asian American and Pacific Islander communities appear to be lacking. A study by the San Francisco Health Department revealed that Chinese, Japanese, and Filipino Americans have a strong awareness of AIDS, but exhibit a "high level of ignorance" about how the disease is transmitted. There is also a degree of disparity in AIDS incidence rates among AAPI subgroups. For example, Filipino Americans have the highest percentage of AIDS cases among all Asian Americans and Pacific Islanders. But, until recently, there has been little data collected on various Asian American ethnic groups, and yet State and Federal agencies have cited lack of statistics about AAPIs as a reason not to fund AIDS and HIV-related research and programs targeting Asian American communities.[3]

Recommendation: HHS must place special emphasis on outreach and education efforts focusing on AIDS in the Asian American community. OCR should spearhead an AIDS awareness and prevention campaign targeted specifically toward Asian Americans. This campaign should include posters, pamphlets, public service announcements, and newspaper publicity targeted toward the Asian American community. All media used in this campaign should be translated into the most commonly spoken languages in Asian American communities. OCR regional staff should work with Asian American civil rights advocacy groups to develop meetings and forums on AIDS prevention and treatment in urban areas with large Asian American populations such as San Francisco and Los Angeles. These forums should be held in health care facilities and treatments centers with speakers who are AIDS medical practitioners and Asian Americans living with AIDS or HIV. To address cultural influences in the Asian American community contributing to misinformation and denial, HHS should create a task force to report on the influence of Asian American cultural traditions on AIDS awareness and prevention in that community.

Finding: The health care system has failed to recognize the effect of the intersection of race/ethnicity and gender on the health status of women of color and their access to quality health care. Minority women in the United States represent many diverse populations, and, in fact, 26 percent of the female population are members of racial/ethnic minorities. On average minority women use fewer health services and are in poorer health than white women.[4]

Recommendation: Researchers, health care providers, and health care advocacy groups must make a concerted effort to include minority women in all of their health care plans and programs. Researchers in particular must be re-

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[3] *See* chap. 2, pp. 28–36.

[4] *See* chap. 2, pp. 47–50.

quired to include diverse women in clinical trials to determine if there are different outcomes when the combined variables of race/ethnicity and gender are factored in. Clinical trial protocols must not assume that women of color will have similar outcomes to all women or all minorities. Further, the offices of women's and minority health within HHS must become committed to advancing the unique needs of women of color, and should take the lead in collecting such data.

Finding: Current data collection efforts fail to capture the diversity of racial and ethnic communities in the United States. Disaggregated information on subgroups within the five racial and ethnic categories is not collected systematically. Further, racial and ethnic classifications are often limited on surveys and other data collection instruments, and minorities often are misclassified on vital statistics records and other surveys and censuses. It is important to collect the most complete data on racial and ethnic minorities, and subpopulations, to fully understand the health status of all individuals, as well as to recognize the barriers they face in obtaining quality health care.[5]

Recommendation: Data collection efforts undertaken by Federal, State, and local governments, as well as private entities, must be as inclusive as possible. To the extent that national estimates are not available for certain minorities, community studies and local censuses can be taken to provide information on those groups. HHS should target smaller health surveys to racial and ethnic subpopulations. Further, NIH and other research grant-funding agencies should encourage and fund studies analyzing the health status of specific subpopulations and disseminate the information in a timely and usable manner. HHS should develop a comprehensive minority health database—including information on health status, service utilization rates, and methods of financing. All operating divisions should be required to contribute to the database information on minority subgroups pertaining to their individual functions (for example, the Health Care Financing Administration should provide information on medicaid and medicare use; the National Institutes of Health should provide disease-specific information; and the Food and Drug Administration should provide information on drug and treatment effectiveness).

The Federal Government must also collect accurate and current data on immigrant populations, in an effort to assess how their health needs differ from other minorities. Such data collection efforts should include information on utilization of health care services and the extent of immigrants' reliance on public assistance. Once these data are collected, they should be distributed to all health care providers and State and local health agencies in regions with large immigrant populations so that they can modify health programs accordingly.

Cultural Competency and Linguistic Barriers

Finding: When cultural competency is not addressed, the provision of health care may be compromised. Lack of cultural competency results in the creation of additional obstacles to health care which in turn result in inefficient and inappropriate use of health care resources. Patients come to rely on the emergency room because they avoid seeing a doctor until medically necessary; they use traditional remedies in addition to or in lieu of Western medicine because of a reluctance to trust the doctor; and they do not comply with prescribed treatments because of a lack of understanding or trust. Cultural barriers to health care exist in the form of misunderstood customs, the inability to express one's health needs, and lack of faith or trust in the health care system.

Furthermore, health care services are often unacceptable to members of minority groups because they have been designed by members of the medical community who are not of the same culture. Culturally competent care is compromised by prejudice, racism, lack of understanding, and cultural myths. The result is that many racial and ethnic minorities attempt to seek care outside the norm of public health care, such as in more expensive private facilities, if they can afford it; through home-based medical remedies or traditional healing processes; or if these are not available options, only when an acute need is present.[6]

Recommendation: HHS and recipients of HHS funding must take sociocultural contexts of

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[5] *See* chap. 2, pp. 50–52.

[6] *See* chap. 2, pp. 52–55.

individuals' lives into consideration when designing health programs if they are to adequately meet the needs of the communities they serve. Medical and health professional schools should educate students about the severity of the persistent racial/ethnic and gender disparities in access to health care and strategies to eliminate such inequities. For example, a medical curriculum could inform prospective physicians and other primary care givers that all Asian Americans and Pacific Islanders or all Hispanics should not be treated as homogeneous groups, because each is a highly diversified group of minorities from widely varied regions and cultures, and with distinct health risks and health concerns. Providers should also be trained to work with language interpreters, identify resources and strategies to help ethnic Americans remain healthy, as well as understand entitlements and legal issues, racial/ethnic classifications, and the influences of culture on health care practices and provider-patient interactions. Training should also address myths and stereotypes about the health status of racial and ethnic groups to make health care providers aware of the erroneous assumptions that are made that negatively affect patients. Most important, education and training to enhance the provision of culturally effective health care must be integrated into lifelong learning for health care providers. All health care providers, administrators, social workers, and anyone who works with consumers in the health care context should receive cultural competency training through continuing education.

Finding: Effective communication between patient and provider is essential to obtaining quality health care. Communication and linguistic barriers that exist between health care providers and other professionals and their customers create a significant problem for members of language minorities in accessing quality health care. Although many individuals have limited English proficiency and cannot effectively communicate with their physicians, there is no statutory requirement that such barriers be addressed or remedied in the context of health care. Yet individuals with limited English proficiency encounter substantial communication problems at almost every level of the health care delivery system, from the administrative level, such as in scheduling an appointment, to the clinical level, such as when attempting to convey symptoms, personal medical history, or a genetic profile to health care providers.[7]

Recommendation: Health care providers and facilities should ensure that language barriers are eliminated through interpreters and translation of materials based on a community's need. HHS should require hospitals to have access to a 24-hour telephone interpretive service, to be used particularly in emergency situations when a qualified interpreter is unavailable or for patients who speak uncommon languages. Individuals charged with translation must be fluent in both English and the patient's primary language, have at least some familiarity with medical terms, and be willing to keep the health care provider-patient interactions confidential. For treatment information, physicians and other practitioners should be required to furnish brochures/pamphlets, forms, records from office visits, and other information to patients in their respective native languages, if they are unable to read and/or comprehend English sufficiently. When printed materials are unavailable, health care providers should be required to provide an oral translation of such information. Providers and health care facilities should also furnish health care information in languages other than English that inform all individuals about efforts that prevent illness and minimize risks.

OCR should provide technical assistance to the facilities in their attempts to provide cultural and language competent care, and should take a more aggressive role in ensuring that limited English proficiency does not hinder the receipt of quality care. Hospitals and other health facilities must recruit more minorities into health professions, which will result in the incorporation of multicultural viewpoints in the science of health and in the delivery of health care. To ensure the recruitment of minority staff and health professionals, OCR should provide technical assistance on the importance of a diverse work force, and how to recruit minority and female staff. OCR should partner with the U.S. Department of Labor and/or the U.S. Equal Employment Opportunity Commission to develop recommendations to improve minority hiring and recruitment practices within the health care industry.

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[7] *See* chap. 2, pp. 53–55.

Finding: Immigrants, and particularly immigrant women, face considerable economic, legal, language, and cultural barriers to health care services. Statutes like Proposition 187 limit, and in some cases eliminate, access to care and have a resoundingly adverse effect on the health status of immigrant communities. Data confirm that, even though it was eventually ruled unconstitutional, the passage of Proposition 187 had a residual effect on the use of health services by immigrants. There was a clear decrease in the number of patient visits after the vote in favor of the statute. This decrease was associated with a subsequent increase in use of crisis services. Immigrants face barriers to health care access not only from the standpoint of language difficulties, but also from less tangible social and legal isolation. Legislation like Proposition 187 and welfare reform have left many unsure of what eligibility standards are.[8]

Recommendation: Medical professionals must take into account differences in cultural values and social roles, along with unique fears and stressors, when assessing the health care needs of the immigrant community. Medical researchers need to conduct studies from both quantitative and qualitative perspectives that can bring understanding to immigrants' daily experiences with regard to their immigration and refugee status, roles, and forms of social support, and how these experiences influence their health, health care access, and health care use. Health care organizations and providers must make efforts to overcome barriers created by the Nation's increasing diversity.

OCR must develop guidelines for health care consumers (particularly immigrants) on their rights, responsibilities, and entitlement to care, in addition to those currently being developed for State health agencies and caseworkers on the effects of welfare reform. These guidelines should be provided in multiple languages and should be simple enough to be understood by consumers who may be less educated or less familiar with the health system and social programs (in other words, not in technical or legal jargon). In particular, OCR Region IX staff must work with the State of California to disseminate information to immigrant communities informing them of their health care rights, and should extend outreach programs so that immigrants are aware of whether they qualify for public assistance.

OCR regional offices should partner with private advocacy groups, community organizations, and relocation sponsors across the country who are willing to assist with the dissemination of information and that have better contact with the targeted groups. For example, OCR staff should work with the many Hispanic and Asian American and Pacific Islander organizations in California and other States with large immigrant populations that have regular contact with immigrant communities. OCR must partner with such groups to ensure that HHS programs have a broader scope and greater impact.

In addition to the outreach and education, HHS must pursue the collection of data and research on the particular concerns of immigrant populations, including cultural differences, special health needs, and financial status as they relate to health coverage, with particular focus on access to care for immigrant children. Research should be done on the effects of welfare reform and health care reform on children in immigrant families, and how access to and effectiveness of health care and other services for immigrants are affected by culturally incompetent care.

Health Care Professionals

Finding: Studies have shown that minority doctors have a positive effect on the health status of minority patients. Thus, a lack of minority doctors may result in limited access to health care for minority patients. Independent of income, communities that have a high proportion of black and/or Hispanic residents are likely to have a shortage of physicians. Thus, because black and Hispanic doctors are more likely than white doctors to practice in poor areas and areas where there is a high proportion of residents of their own race or ethnic group, minority doctors fill an important role in the community. Further, a decrease in the number of physicians from minority groups may result in reduced access to health care, reduced health, and reduced well-being for a large portion of the minority population.

Similarly, minority dentists in private practice are more likely than whites to provide free or reduced rate dental care to patients who may

[8] *See* chap. 2, pp. 52–55; and chap. 3, pp. 77–78.

have difficulty in paying for, or otherwise obtaining, dental care. Private practitioners who are members of minority groups are more likely to provide free or reduced rate dental care to migrant workers. At the same time, minorities who went to dental school have lower income, less prestigious jobs and, in the case of blacks, are less likely to actually be practicing dentistry than whites. Minority dentists are also less likely to be specialists than whites. Because there are so few minorities currently in medical and dental professions, there is a relatively small support network of mentors.

In much the same way that minority physicians have had a positive effect on minority communities, women physicians have the potential to positively affect on female patients. Similarly, despite gains women have made in entering health professions, women still are clustered in specific areas of medicine, and remain poorly represented in the field of medical research. Women physicians are often steered to areas of general practice and primary care, while men are more likely to enter the richly rewarding surgical subspecialties. Hispanic women are still severely underrepresented, making up less than 2 percent of those in health professions requiring advanced degrees. Increasing the numbers of women in medicine can encourage the development of multidisciplinary and community-based curricula, contribute to the expansion of information on women's health, and increase attention to women's health research.[9]

Recommendation: Because they are clearly handling a disproportionate amount of the burden of providing medical services to those unable to pay, minority dentists and physicians should be compensated for their efforts through Federal and State reimbursement. HHS and Congress should work together to develop tax incentives, funding programs, or other methods of rewarding health care practitioners who demonstrate a proven record in providing needed services to underserved populations. Health care organizations, advocacy groups, and other organizations that serve minority communities also should provide grants and fellowships to provide financial and other assistance to physicians, dentists, nurses, and other health care professionals serving disadvantaged groups and practicing in minority communities.

Federal scholarships, fellowships, and subsidized loans should be made available for underrepresented minorities and women to be able to attend medical school. Congress should legislate a program and allocate funds for HHS and the Department of Education (DOEd) to distribute to institutions that show a commitment to increase minority and women representation. Similarly, States and private organizations also should fund scholarships for minorities and women to attend medical schools.

Further, as an incentive for attending medical and dental schools, as well as a way to ensure future improvements in medically underserved areas, HHS should develop a medical corps program in which costly medical school tuition is paid for by the Federal Government in exchange for an agreement that the student will serve in minority and poor communities for the first 3 years of his or her medical practice. This program, similar to the National Health Service Corps, would be specifically targeted toward students, minority or not, who are willing to make the commitment to serve underserved populations at the onset of their medical careers. A program like this will also serve to eliminate the financial barrier to medical education experienced by many minority students.

Additionally, in order to level the playing field, HHS, through the Office of Minority Health (OMH), should establish a minority medical professional mentoring and placement program to assist minorities with career opportunities, such as finding residencies and jobs after completion of training. Medical and dental schools should try to place all students, but particularly those who are underrepresented, with mentors who can assist in career planning and development. To guide this effort, OMH should develop a formal, structured mentoring program in which all health professional schools can participate. OMH should develop guidelines on how to develop a mentoring program, relying on examples of programs that have been proven to be successful. These guidelines should be made available to all health professional schools. Further, professional organizations, such as the American Medical Association, the American Dental Association, and the American Association of Medical Colleges, should develop a com-

[9] *See* chap. 2, pp. 60–63.

prehensive list of professionals who are willing to serve as mentors. Similarly, HHS' Office for Women's Health (OWH) should develop a similar or joint program, partnering with professional groups such as the American Medical Women's Association.

HHS must not only encourage, but require medical training programs, particularly those in racially and ethnically diverse regions of the country, to actively recruit minority students. Educational enrichment programs must begin at the elementary level and continue through secondary education. HHS should partner with the Department of Education (DOEd) to identify those schools that would benefit most from such advanced science programs.

Further, because women already make up nearly half of current medical students, recruitment into medical school is not the issue; rather, efforts should be made to recruit women into specialty areas of medicine and to place women into diverse fields. Medical schools must, however, increase the numbers of minority women, particularly Hispanic women, admitted to medical education programs. Joint HHS/DOEd science-oriented educational programs at the elementary and high school levels should emphasize medical professions for these women, who are often neglected in education and who, on average, have lower levels of educational attainment.

Finding: Women face difficulty breaking into medical research, and this is compounded by the uneven distribution of grant support. Women receive only 21.5 percent of all research project funds, and their grant awards are, on average, $30,000 less than those of male researchers. Uneven distribution of funds based on gender is a blatant civil rights violation. Further, women face additional difficulties in biomedical careers, such as low visibility and the lack of role models and mentors, sex discrimination and sexual harassment, family responsibilities, and reentry into a biomedical career after professional separation.[10]

Recommendation: To assess the reasons that women scientists are underfunded, the offices of women's health in the operating divisions and the Office of Public Health and Science should initiate a comprehensive review of unsuccessful grant applications, to determine whether the deficiencies are in the applications themselves or whether the review process is flawed in favor of male applicants. HHS must mandate that women scientists are awarded grants at the same ratio as men, based on their application numbers. In other words, funding for women scientists should be raised to match the average for the success of all proposals. Because they have only recently entered medicine in large numbers, HHS and the major grant-making operating divisions, particularly the National Institutes of Health (NIH), must provide technical assistance to female scientists on the application process and review procedures.

HHS also should provide technical assistance to all applicants, particularly minorities and women, on the availability of grants and research funds so that they are made aware of research opportunities, even if they are not a part of the scientific network that has traditionally been dominated by male researchers. The offices of women's health within the major grant-funding agencies should be responsible for providing coordination and leadership and should serve as an internal and external contact point for information regarding the equitable distribution of research funds. Further, operating divisions must require more detailed information on the race/ethnicity and gender of researchers, not just the principal investigators, during the application process. Operating divisions should review this information annually to ensure that minorities and women are significantly represented in the scientific community as researchers.

Health Care Facilities

Finding: Teaching hospitals play a major role in serving underserved populations. In fact, 52 percent of patients hospitalized in major teaching hospitals are either medically indigent or of a racial or ethnic minority group. Further, as the number of uninsured or underinsured people in the United States continues to grow, and hospital survival increasingly becomes a business venture, teaching hospitals will be less able to provide care to these populations in the future.[11]

[10] *See* chap. 2, p. 62.

[11] *See* chap. 2, p. 63.

Recommendation: Federal, State, and local governments should allocate funds to ensure that the hospitals' infrastructures are adequate to address the needs of the populations being served, with up-to-date equipment and high quality accommodations. Further, HHS should draw upon the unique resources available at teaching hospitals, such as medical students, faculty, and advanced technology, to fund and implement innovative programs. For example, HHS should allocate additional funds to those hospitals that have made a commitment to reaching minorities through community health programs or that operate health clinics and centers in the community. The programs that prove successful should then be replicated at other facilities.

However, because of the potential effect teaching hospitals can have on minority and low-income patients, it is necessary that OCR pay close attention to teaching hospitals, and hold them to the highest civil rights standards. Compliance reviews must be done on a regular basis and OCR should make an ongoing effort to provide technical support and outreach to these facilities.

Health Care Financing

Finding: Some commentators caution that as the health care system moves to a new form of organization—managed care—there may be incentives for policies that will result in discrimination. The premise behind managed care could result in discrimination against those whose care is costly and could ultimately lead to the segregation of racial and ethnic enrollee groups into health care groups that are less accessible and of poorer quality. For example, managed care plans can limit their service areas to suburban areas, which tend to have a smaller percentage of minority residents than inner cities. Plans also can select which health services providers to contract with, potentially leaving out providers who have traditionally served minority populations.

As private insurance increasingly becomes under the control of managed care organizations, assistance to those without health insurance may disappear. The combination of the rising numbers of uninsured and growing managed care penetration is undermining the ability of providers to continue to provide care to the uninsured. As physicians become affiliated with managed care organizations and larger group practices, they have less control over the patients they see in practice arrangements that are more formal and that serve a defined population. As a result, physicians have less latitude to provide charity care to members of the community who cannot afford health care.

Doctors who serve poor and minority patients will not fare well in a managed care environment. When making decisions regarding the selection or dismissal of physicians, HMOs value cost effectiveness in addition to medical quality. They value doctors who perform few procedures, order a low number of prescriptions, and minimize referrals. Because physicians serving poor and minority communities are faced with a high percentage of sick patients who often require more intense and costly services compared with healthier groups of patients, these physicians will be less attractive to managed care networks.[12]

Recommendation: Federal Government, States, managed care plans, and private accreditation agencies must work together to ensure not only that quality care is being provided, but that minorities and women are equally participating in and benefiting from managed care. Enrollment numbers and geographically targeted areas must be examined to ensure equal provision for traditionally underserved populations. In addition, States should be responsible for establishing their own quality assurance mechanisms to monitor managed care programs within the State, with particular emphasis on medicaid managed care programs. For example, Minnesota has created a State Office of Health Care Consumer Advocacy and Information to answer questions for consumers and resolve problems as they arise. The office is also responsible for reviewing basic processes and operational procedures and contracts, making site visits to HMO clinics, conducting financial audits, and investigating complaints against HMOs. These State quality assurance boards should be required to submit annual progress reports to OCR regional offices outlining the extent of their involvement with State managed care programs and giving a progress report on the investigations and corrections of violations. They should also be required to provide data on the race, ethnicity, and gen-

[12] *See* chap. 2, pp. 64–69.

der of managed care enrollees and the plans in which they are enrolled.

Physicians need incentives to provide charity care. In some cases local governments finance charity care with local tax dollars because communities have a vested interest in the health of their residents, but this is costly and many local governments do not have excess funds. State and Federal governments should develop programs that address this issue. Possibilities include matching funds to facilities and providers who provide a set amount of charity care, prepaying charity care from the medicaid budget, and providing incentives for private hospitals to absorb some of the burden of charity care from public and teaching hospitals.

To ensure that physicians are not excluded from plans based on the populations they serve, OCR must develop guidelines which require that an adequate number of minority-serving providers are included in any given network. Further, managed care groups must not be permitted to use cost effectiveness as a reason for excluding certain practitioners when that exclusion will have a disparate impact on minority or women patients.

OCR must require all managed care networks to follow specific guidelines for enrollment so that women and minorities are not excluded from participating in and receiving managed care benefits. In addition, providers who serve minority populations must be safeguarded against discrimination by managed care plans. OCR should establish guidelines requiring that when plans are selecting providers with whom to contract, there must be adequate representation of minority physicians and minority-serving physicians. Further, OCR should forbid networks from requiring providers to sign exclusive contracts as a condition of participation in the network. In this way, physicians will have the option of signing multiple contracts with plans that have a more diverse group of enrollees. Also, plans should be encouraged to include nonphysician providers (for example, nurse practitioners) in an expanded network to be offered to enrollees. Not only will enrollees have greater choice in who they select as health providers, but this will open access to smaller facilities and community health centers that are primarily staffed by nonphysician health providers. OCR must provide State officials and officials in the health care industry guidance on the unlawful practices within managed care as well as areas of potential violation. OCR also must require managed care networks to tailor services to racial and ethnic minority groups and include a diverse group of providers so that enrollees can choose a provider with whom they feel comfortable and who can provide culturally sensitive care.

OCR must develop guidance on how responsibilities under civil rights legislation apply in the managed care setting. OCR must then work in conjunction with health care providers who participate in the networks to ensure that the needs of minorities and women are not being ignored by selective practices of the managed care networks. Further, to ensure that the new health care system revolving around managed care does not perpetuate and deepen practices found in the old system, OCR must require State agencies and other recipients of HHS funds to collect information on plan structures, care processes, and treatments for all groups served. OCR must also ensure that data collection in this area adequately reflects the effect of managed care on women and minorities. For example, the data collection efforts of the Health Care Financing Administration (HCFA) and the Health Resources and Services Administration (HRSA) should be reviewed by OCR to determine to what extent more relevant data can be obtained and to ensure that civil rights are addressed in the managed care environment.

Finding: One limitation of public insurance as compared with private coverage is the amount of physician reimbursement for services. Current public insurance programs emphasize the need for cost containment and include restrictive eligibility levels, low reimbursement rates, and cost-sharing requirements (through deductibles and copayments), all of which can limit access to necessary health care, to the particular detriment of women and minorities. Health care plans with low reimbursement levels create a financial incentive for health care providers to avoid treating minority and indigent individuals altogether, or to treat such individuals inappropriately and provide them with less medical care than their health status warrants. It may also lessen the likelihood that providers will make referrals to specialists or provide care that is not covered by public insurance. Copayments and

deductibles may also discourage low-income individuals (usually women and minorities) from use of preventive services, and may compel them to delay obtaining essential medical care. Delaying care until conditions become emergencies that require more extensive and costly treatments increases the Nation's medical expenditures over the long run.[13]

Recommendation: Congress must either increase the reimbursement rate for physicians serving medicaid patients so that it is comparable to private insurance, or require all physicians to serve an equal number of medicaid patients so that a few do not absorb the financial burden. In addition, medicare and medicaid coverage must cover the same range of services and treatments as private insurance, and the range of services covered should be based on the needs of the enrollees. For example, if medicaid enrollees are more likely to need preventive care, such as high blood pressure and breast cancer screening, then this service should be explicitly covered.

Chapter 3: Gender, Race, and Ethnicity—Experiences with Three Health Care Related Issues

Summary

Women and minorities are adversely affected by discriminatory practices and differential treatment in the health care setting. Of particular importance is the degree to which health care is accessible. Access to quality health care is affected by a variety of factors, including availability and quality of health care service delivery, availability of financing, and the extent to which research includes various subgroups. Unequal access to health care services, financing, and research translates into racial, ethnic, and gender differences in health status in the United States. Inequalities in income, education, and occupation account for some of the race- and gender-related differences in health status and access to health care, but those factors alone do not account for all disparities. Failure to recognize and eliminate differences in health care delivery, financing, and research presents a discriminatory barrier that creates and perpetuates differences in health status.

Differences in health status reflect, to a large degree, inequities in preventive care and treatment. For instance, African Americans are more likely to require health care services, but are less likely to receive them. Racial disparities have been found in the likelihood of undergoing bypass surgery, receiving a kidney transplant, and other life-saving procedures. Differences also exist in the number of doctor's office visits between whites and blacks, even when controlling for income, education, and insurance. Furthermore, researchers have concluded that doctors are less aggressive when treating minority patients.

Inequities exist along gender lines as well. For example, there are statistically significant differences between the amount of time males and females wait to see a physician in the emergency room, with females waiting longer. Experts in health research acknowledge that women's health issues frequently have been overlooked, particularly those of minority women who often have low-paying jobs with no insurance, and thus have poorer health than other women or men. For minority women, health status is affected by income, employment, and other factors that are compounded by the intersection of race, ethnicity, and gender.

These differences are just a few examples of the many that reflect discriminatory practices. To facilitate greater understanding of disparities based on race and gender within the health care system, it is necessary to look at the experiences of minorities and women. These inequities reveal the importance of applying vigorous civil rights enforcement efforts to the Nation's health care system. Inequities in access to quality health care may be observed in three broad contexts: delivery of services, availability of financing, and appropriate research on health-related issues. Lack of insurance, lack of transportation, cultural barriers in the form of misunderstood customs, language difficulties, and stereotypes all affect the quality of care received.

Discriminatory policies and practices can take the form of medical redlining, excessive wait times, unequal access to emergency care, deposit requirements as a prerequisite to care, and lack of continuity of care, which all have a negative effect on the type of care received. Because discriminatory practices are often facially neutral, citing exact practices becomes a difficult

[13] *See generally* chap. 2, pp. 65–69; *see also* chap. 3, pp. 91–109.

task. There are many examples, however, of policies and practices that disproportionately affect racial and ethnic minorities, such as refusal to admit patients who do not have a physician with admitting privileges at that hospital, exclusion of medicaid patients from facilities, and failure to provide interpreters and translations of materials, to name a few.

In addition to these barriers restricting access to health care for racial/ethnic minorities, there are barriers to care that predominantly affect women. There are also gender differences in medical use, provision of treatments, and inclusion in research. This is partly the result of different expectations of medical care between men and women and of gender bias of health care providers. Furthermore, the difficulty women face accessing adequate health care, and all its components, is not limited to illnesses that affect both male and female populations. Rather, there is evidence that women often find it difficult to access quality health care related to gender-specific illnesses such as breast cancer.

An additional symptom of gender bias in the health care system that can affect outcomes is the way in which women's medical concerns are not taken as seriously as men's and are often dismissed as the result of emotional distress or as a psychosomatic condition. Further, some women's health issues, such as violence against women, have been largely ignored by the medical community, and seen primarily as a social issue, not necessarily a health issue. Part of the problem is that medical professions have historically lacked a female perspective, in much the same way that the minority perspective is missing, therefore giving little attention to women's health concerns.

Another restriction to health care access, which is disproportionately experienced by both women and minorities, is the ability to pay for services. As the cost of health care continues to rise, many Americans find that they cannot afford coverage, nor can they afford services. The majority of those without health insurance are minorities and/or women. Without health insurance, individuals are not likely to receive appropriate care. Financing for health care is provided by a number of entities: employer-provided health plans, privately purchased insurance, and public assistance in the form of medicaid and medicare. The high cost of private insurance precludes many women and minorities from being able to afford it. Women and minorities also are less likely to be employed in jobs that provide health insurance as a benefit, and therefore they are often forced to go uninsured, particularly if the wages they earn disqualify them from receiving public assistance, making them "the working poor."

Public insurance in the form of medicaid fills some of the gap between the privately insured and the uninsured, but does little to ensure that those relying on public insurance are afforded the same high standard of care as those who are privately insured. Although medicaid improves access for those with more serious health problems, it goes only half way toward providing the same level of care that private insurance provides. Because minorities and women rely more on medicaid, they are disproportionately more likely to have less adequate care. The development of public assistance programs has shifted the focus away from the inability of patients to pay toward a more subtle racism that cannot be easily untangled from the economics of the provision of health care.

Researchers have noted that not only does the receipt of health services vary according to insurance coverage, but that there is a correlation between coverage and health outcomes. For example, in the case of breast cancer, women with medicaid and uninsured women have higher rates of morbidity and mortality due to the fact that hospitals that treat large numbers of these patients often provide less thorough screening processes. Uninsured and medicaid women have significantly more advanced stages of the disease when initial diagnosis is made.

In 1996 welfare reform changed the structure of public assistance and, as a result, had a disparate impact on women and minorities. One of the direct effects of welfare reform has been a reduction in the use of medicaid by those who qualify, because of an unawareness of eligibility requirements, which has increased the number of uninsured. A second effect has been that the subsequent increased poverty among those in need of assistance has caused a worsening of health status and an increase in the need for health care services.

The health condition of women and minorities will continue to suffer until they are included in all types of health research. Billions of

dollars are spent each year on health research ($35 billion in 1995). However, a strikingly minute percentage of those funds are allocated to research on issues of particular importance to women and minorities, and to research by women and minority scientists (21.5 percent and .37 percent, respectively). In response to years of exclusion of minorities and women, several statutory requirements have been enacted to ensure that research protocols include a diverse population.

Lack of inclusion has the significant effect of lessening the ability to generalize research findings. Broad-based inclusion of minorities in clinical trials is a civil rights issue as well as a sociopolitical one. Despite volumes of literature suggesting the importance of race, ethnicity, and culture in health, health care, and treatment, there is relatively little information available on the racial, ethnic, and genetic differences that affect the manifestations of certain illnesses and their treatments. Based on a history of exploitation by and mistrust of the medical community, many minorities are not willing to participate in clinical trials.

Women also traditionally have been ignored as subjects in clinical trials. Consequently, there is relatively little knowledge about the gender-specific effects of drug therapies and other treatments in the provision of health services for women, even for illnesses that affect women at rates equal to or greater than for men. The misinformation resulting from gender-biased research is potentially life-threatening. The lack of research contributes to a lack of knowledge about prevention and treatment procedures, leaving health care providers to rely on speculation and assumptions when it comes to women's health needs.

Health Service Delivery

Finding: Despite the existence of civil rights legislation, equal treatment and equal access are not a reality for racial/ethnic minorities and women in the current climate of the health care industry. Many barriers limit both the quality of health care and utilization rates for these groups, including geographical distances, shortage of primary care providers in minority communities, and discrimination.

Additionally, members of racial and ethnic minority groups disproportionately face multiple restrictions to health care services delivery, including lack of insurance, lack of transportation, difficulty taking a day off of work to get health care services, finding child care while in the hospital, and paying for services such as nursing homes.[14]

Recommendation: First and foremost, OCR must increase its enforcement efforts to specifically identify and remedy title VI, title IX, and Hill-Burton violations. Further, OCR needs to serve as the facilitator between those in need of better services and those that provide such services. For example, OCR should identify those community and other health programs that have been effective in improving access to quality health care, outline the reasons for their success, and then make that blueprint available for replication at other facilities. There are innovative programs at the local level that have worked; perhaps a "mentoring" partnership program could be established between health care facilities, in an effort to exchange ideas and methods for enacting them.

Because resources often serve as a barrier to implementing these programs, OCR should ask HHS to allocate funds, which would be disseminated and monitored by OCR, for those facilities that demonstrate a commitment to implementing programs that would not only ensure civil rights compliance, but would incorporate civil rights enforcement and improved access to quality care into the daily functions of the facility. Programs of this nature could be modeled after the Centers of Excellence Program implemented in the Office of Public Health (PHS) and Science's Office of Women's Health, where funds are given to those institutions that have demonstrated a commitment to women's and minorities' health issues. HHS should provide funding to facilities that are willing to share their ideas and programs with other facilities and to assist in the replication and implementation of similar programs. Such programs should be extended to community health facilities in addition to major teaching hospitals and medical schools. With assistance from HHS and the Offices of Minority Health and Women's Health, OCR could identify those facilities with a proven track record for commitment to addressing the needs of women and minority patients.

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[14] *See* chap. 3, p. 73.

Finding: Research has shown that minority and low-income patients have fewer mammograms, influenza immunizations, and visits to physicians for ambulatory care. However, these groups have higher hospitalization rates, higher mortality rates, and greater instances of amputation. In addition, statistical analyses have documented discrepancies in access to long-term care, with nonwhite patients experiencing longer delays than white patients in being placed in nursing homes. Even after controlling for several factors, including patient age, gender, health conditions, special care requirements, behavior, financing, and cooperativeness of family, racial differences persist in the wait time to be discharged from a hospital and placed in a nursing home.

Overt discrimination and policies that result in disproportionate impacts on certain groups further deteriorate the health care services available to and received by racial and ethnic minorities. For example, different access to medical care may be manifested in differences in wait times among blacks and whites, and males and females. Because white patients are more likely than black patients to have seen a private physician before going to the emergency room, their conditions may be considered more serious than those of patients who have not previously seen a doctor. However, there is little data to justify that this perception should result in longer wait times. There are many other examples of facially neutral policies and practices that disproportionately affect racial and ethnic minorities, such as refusal to admit patients who do not have a physician with admitting privileges at that hospital, requiring a deposit in order to treat a patient in the emergency room or to admit a person for inpatient care, and inquiring into a patient's citizenship, national origin, or immigration status before admitting that patient to the hospital.

When examining the reasons for differences in health status and access to care, researchers tend to cite cultural differences, undocumented patient preferences, or a lack of information about the need for care as determinants. The alternative explanation is racism—that is, racially discriminatory rationing by physicians and health care institutions. However, if racism is involved, it is unlikely to be overt or even conscious, making it more difficult to identify.[15]

Recommendation: OCR must take its enforcement efforts seriously and address the underlying health care structures that foster racism and sexism, including the obvious barriers such as financing, as well as the more elusive barriers such as prejudice, stereotyping, and cultural ignorance. If OCR continues to focus its enforcement on the more tangible civil rights violations, without delving into the reasons they exist in the first place, it will fail to recognize and eliminate the true sources of inequity. OCR must conduct broad-based, systemic compliance reviews on a rotating basis in *all* federally funded health care facilities, at least every 3 years. These compliance reviews must be comprehensive onsite investigations. OCR should work with the Joint Commission for the Accreditation of Health Care Organizations and other accreditation entities to develop legally mandated civil rights guidelines to be used in their reviews and evaluations of health care facilities. OCR should also develop and enforce severe penalties for actual civil rights violations, and intervene when potential violations present themselves. OCR must follow up its findings with the requirement of mandatory revision and/or repeal of any discriminatory practices or policies if facilities wish to continue receiving Federal funds.

OCR also should develop guidance materials on practices that are potentially discriminatory and provide technical assistance to hospitals and other medical facilities on how to identify potentially discriminatory policies and develop nondiscriminatory policies. For example, OCR guidelines should specify that health care providers must not be allowed to refuse patients based on a physician's admitting status, require a deposit before rendering emergency care, refuse to deliver any baby, exclude medicaid patients, or inquire into a patient's immigration or citizenship status.

In addition, OCR and other HHS agencies should use existing research outlining disparities in health status and access to health care and incorporate this information in the development of civil rights policies and civil rights enforcement programs. For example, the infor-

[15] *See* chap. 3, pp. 78–91.

mation from these studies could be incorporated into data collection instruments, such as surveys, that would then be used by HHS and State and local governments to review the practices of providers and individuals who apply for Federal assistance. This would include information on patient assignments, standard medical services, and the type of treatment offered based on race, ethnicity, and gender. The addition of some of these factors to data collection instruments could detect, at an earlier phase, potential discriminatory problems at a facility, and secure compliance to remedy such problems before awarding funds.

To identify the cause of discrimination, researchers must ask the following questions: What choices are black patients and white patients actually offered by their physicians? What do they hear? Do their physicians make specific recommendations? Do the patients participate fully in the decisionmaking process? What criteria do physicians use in making clinical judgments? Are they applied equitably, or are they subtly influenced by racial stereotyping on the part of time-pressured physicians, reinforced both by institutional attitudes and unwarranted assumptions about prevalences and outcomes? Once questions like these are widely asked in research, the results will be much more useful in identifying civil rights compliance. Researchers need to focus attention on possible sources of discrimination, such as the assumption that minority patients are unable to pay for services, the prejudicial biases of admissions personnel, and the unavailability of translators. When viewed in this light, different treatment demands attention as a civil rights violation. OCR must address these policies and practices in a vigorous, consistent manner.

Finding: Many reports have detailed the inequities confronting racial and ethnic minorities in the health care system. For example, a series of articles in *Newsday* chronicled the disparities in health care on Long Island, New York. After a year of analyzing hospital records and databases and conducting research on health care in the region, reporters came to the following conclusions, many of which have been reached by other researchers: compared with black patients, whites receive more advanced and intensive treatment; blacks are more likely than whites to receive more radical, severe treatments, such as amputation; blacks wait longer for kidney transplants than whites; and stereotypes about the treatment of minorities pervade the medical community. To carry out the investigation, *Newsday* reporters did a behavioral risk study of more than 2,000 residents on Long Island and in Queens to parallel those that have been done on the national level. They also extensively analyzed databases covering every hospital admission in New York State over 7 years, including information about doctors and insurance companies. These methods proved effective.

As a result of the *Newsday* publication, OCR in Region II began a series of investigations into the condition of health care in the Long Island hospitals. Certainly, it can be argued that OCR should have had the foresight to recognize the disparities uncovered before they became as rampant as the newspaper's investigation suggests. However, the quickness with which Region II responded to the allegations should be commended.[16]

Recommendation: All OCR regions must stay in tune with practices in their areas and should use local researchers, advocacy and community groups, and media as resources for uncovering barriers and civil rights violations in health care. Local organizations and advocacy groups, as well as OCR, should undertake studies that are area-specific to identify broad-based discrepancies or disparities within their jurisdictions. For example, organizations representing women and minorities should sponsor research on disparities and discriminatory practices and policies in health care. These organizations should make grants available for nonbiomedical research such as longitudinal studies of changes in health care and testing for civil rights violations. Such studies should be incorporated into the standard compliance review procedures of OCR investigators.

Gender Bias in Health Care Services

Finding: Gender bias extends to all areas of health care, but is perhaps most visible in the inequities with which women are treated as patients. The gender differences in medical utilization and treatments may be the result of gender-related biological differences that have been obscured by the exclusion of women from research,

[16] *See* chap. 3, pp. 79–80.

different expectations of medical care between men and women, or gender bias by health care providers. Women tend to undergo more examinations, laboratory tests, and blood pressure checks than men, but are less likely to receive major diagnostic or therapeutic interventions. The rates at which procedures are performed may be influenced by physicians' perceptions of gender-related differences in risk and efficacy.

Perhaps one of the most telling causes of gender-based inadequacies in treatment, particularly for specific diseases that affect both sexes, is the historical lack of research on women's health issues. Medical practitioners are often unaware of differences in disease rates, treatment effects, and outcomes simply because there is a dearth of information available to them. This lack of information also extends to the way in which health care services are delivered in a gender-incompetent manner. But the problem of inadequate health care for women is much more deeply entrenched in the paternalistic nature of the health care industry, from the way medicine is practiced to health care financing to health care policy.[17]

Recommendation: HHS, with the legislative and financial power to significantly affect all aspects of health care in the United States, must reassess its agenda to include women's perspectives and reevaluate the methodology of health care. The Office of Women's Health in PHS and the individuals responsible for women's health coordination in the operating divisions should take a more proactive role in the incorporation of women's health issues in HHS. These offices suffer from the usual affliction of peripheral offices in that they have extremely limited budgets. HHS must recognize the potential effect of these offices and should increase their funds and extend grant-making authority to at least the Office of Women's Health at the departmental level, if not all offices of women's health within HHS.

The Office of Women's Health and OCR should work together to identify the areas of health care practice that are potential civil rights violations for women, and OCR must make the evaluation of gender-neutral policies an integral part of compliance reviews and pre- and postaward reviews. For example, in the course of a review, OCR should collect information, on a regular basis, about the diagnostic and treatment referrals made to men and women with similar health conditions to determine if a facility consistently provides different treatment on the basis of sex.

Further, HHS, and OCR in particular, must include women's health advocacy groups as partners in health policymaking. This approach, if done inclusively, will ensure the representation of diverse groups of women and will facilitate communication between policymakers and health care consumers. Women's issues must be attended to in health care policymaking beyond expanding biomedical research and developing new medical treatments: they must include the basic questions of whether and how women can access health information and services that will enable them to improve their health.[18]

Finding: Studies have found discrepancies in the treatment of breast cancer on the basis of race/ethnicity and socioeconomic status. Minority women have higher death rates from cancer and receive less breast care than other groups. Women in lower income groups are less likely to receive breast cancer information and screening than other women. Studies have indicated that black women receive different breast cancer treatments than white women, doctors are less likely to recommend breast cancer screening for Hispanic women, and breast cancer often is undetected and untreated in the Chinese American community.

The interplay between race/ethnicity and lack of private insurance compromises the accessibility of thorough preventive and maintenance-related health care. Many necessary treatments, including breast cancer examinations and mammograms, are not explicitly covered by medicaid. Even when such services are available to medicaid patients, there are no requirements for physicians to provide periodic breast cancer screenings. Because breast cancer is a disease that is to a large degree curable if caught in the early stages, it makes sense that women should be provided with adequate screening and early treatment options. However, because hospitals that care for large numbers of uninsured pa-

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[17] *See* chap. 3, pp. 84–91.

[18] *See* Carol S. Weisman, *Women's Health Care* (Baltimore, MD: The Johns Hopkins University Press, 1998), pp. 201–04, 218.

tients and medicaid patients often use less thorough screening processes, these patients have higher rates of morbidity and mortality from the disease. Uninsured women and women covered by medicaid have significantly more advanced stages of the disease than privately insured women when initial diagnosis is made.[19]

Recommendation: Illness screenings and related treatment should become part of the regimen covered by public insurance and must be provided to those who have no insurance. Congress and HHS should revise medicare and medicaid coverage to include the costs of breast cancer screening, taking into account differences in types and frequency of screening procedures necessary by age and race/ethnicity. In addition, breast cancer and other health concerns specific to women, such as reproductive health, must become recognized as primary care and not specialty services. Not only will this improve the health of these populations in the long run, but it will be economically advantageous to provide such care because treatment in the early stages of many diseases is less costly.

HHS has devoted a substantial amount of resources to breast cancer research and education and, in fact, these efforts have proven successful—for nonminority, economically advantaged women. HHS must ensure that information on preventive measures and screening is available to *all* communities. HHS should make an effort to address community groups, minority and women's organizations, schools, churches, and other institutions that can assist in reaching different populations, and should conduct outreach, education, and technical assistance activities to ensure that individuals are informed about important health issues. Because women who do not have access to a primary care physician are less likely to have access to the most common forms of screening such as mammograms, HHS must work in conjunction with hospitals and community centers not only to provide free screening to all women, but to make that screening easily accessible.

Finding: Inequities in treatment are further fueled by the role of gender in the physician-patient relationship. Studies evaluating the relationship between the gender of the physician and the offering of gender-congruent diagnostic procedures, such as breast exams, Pap smears, and mammograms, have indicated that gender bias does indeed exist. Women who report having a male physician are less likely to receive these procedures than women who have a female physician. Women physicians are more likely to exercise greater diligence in offering screening tests, and women patients are more likely to follow through with obtaining tests suggested by women physicians. Because communication is fundamental to achieving the intended goals of health care, the relationship between the patient and provider is central to the process of health care delivery.

An additional symptom of gender bias in the health care system that affects health outcomes is the way in which women's medical concerns are not taken as seriously as men's, if not trivialized altogether. In a recent study, one out of four women stated that they had been "talked down to" or treated like a child by their physician, and nearly one out of five women had been told that a reported condition was "all in her head." Women's complaints are dismissed by doctors far too often. One study found that primary care physicians judged 65 percent of women's symptoms to be influenced by emotional factors and women's complaints were more than twice as likely as men's to be identified as psychosomatic.

Further, many gender-specific health concerns such as domestic violence have been ignored by health care providers. Since providers are not adequately trained in holistic care for women's health problems, including sexual abuse or domestic violence, they have been neglected in research and clinical practice. Although health care providers are in a unique position to detect abuse, they often do not give appropriate care.[20]

Recommendation: Gender sensitivity training should become part of the medical school curriculum. The Office of Women's Health in the Office of Public Health and Science at HHS should work with women's health organizations and professional groups to develop and implement national curricula on women's health issues and holistic approaches to medicine, including training on specific issues in women's primary care at different life phases.

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[19] *See* chap. 3, pp. 104–05.

[20] *See* chap. 3, pp. 84–91.

Male physicians in particular must be made conscious of differences in health care needs, including the method by which medical care is provided. All physicians who are credentialed to serve as primary care providers for women within managed care programs or other health systems must be required to demonstrate appropriate training and competency in women's health care.[21] State licensing boards should require gender and cultural competency as necessary elements for licensure of all medical professionals. Women's health organizations and advocacy groups should play an integral role in the development of curricula that ensure the needs of all groups of women are being represented.

In addition, approaches to specific women's health issues, such as domestic violence, need to be incorporated into medical training programs. Health care professionals need to view domestic violence as a health care issue, not just a social problem. The American Medical Association has strongly advocated the inclusion of domestic violence training for practicing physicians and has worked toward changing the climate of women's health care so that this problem is not only identifiable, but solvable. Because domestic violence is so widespread, primary care physicians must make screening a part of routine care.

The Office of Women's Health in the Office of Public Health and Science has recognized domestic violence as a serious health issue, and domestic violence is identified as a health concern in the objectives of Healthy People 2010. As such, HHS should provide the Office of Women's Health with additional resources to tap into the health care profession and assess the deficiencies that exist in the treatment of domestic violence and assault in the medical industry.

Health Care Financing as a Socioeconomic Barrier to Care

Finding: Findings presented in this report demonstrate that one of the most pervasive determinants of whether an individual will receive health care is the ability to pay for services. Despite good economic conditions and a strong private market, more than 42 million Americans are without health insurance and this number is expected to grow. Persons without health insurance are less likely to: (1) have a usual source of health care, (2) receive preventive health care services, and (3) have their health care needs met. Insufficient insurance coverage, can also result in inadequate care. Moreover, if the uninsured are a sicker population than their insured counterparts, then this poses a more serious health problem because persons with the most need for health care are also the least likely to receive it. Reasons for the decline in the number of persons with health insurance include rising costs for health care and decreases in real family income and hourly wages. In addition, employers have increased the number of part-time and contract positions, which usually do not receive health benefits.

Low-income persons often face difficulty locating a provider willing to serve them. Similarly, lower income individuals are likely to encounter difficulty finding health care plans they can afford and are less likely to have employer-provided health insurance coverage. Even when low-income individuals have health insurance, it is often inadequate, with high premiums and deductibles, and limited coverage, particularly for costly specialty procedures. This reality begs for government intervention. Ensuring financial access to care for *all* Americans will greatly improve the health of the Nation, but will have a particular effect on minorities and women who are more likely to be among lower income groups and to be uninsured. Thus, an inclusive public insurance policy is necessary to address financial and socioeconomic barriers to care, as well as to remedy the adverse effects of such barriers for racial/ethnic minorities and women.

Although medicaid improves access for those with more serious health problems, it does not provide necessarily the same level of care that private insurance provides. Thus, minorities and women, those most likely to receive medicaid, are more likely to have less adequate care. Further, many adults do not qualify for medicaid, yet cannot afford private health insurance. It is often assumed that people without private insurance, medicaid, or medicare nonetheless find health care. It is assumed they may be inconvenienced by the form and location of the services, but that they still have access. This is not the case. Although emergency rooms in hospitals that accept medicare are legally obligated to provide emergency services, other private health

[21] Weisman, *Women's Health Care*, p. 222.

care providers have no such obligation. Long waiting lists for the few public services available to the uninsured poor mean that they sometimes either never obtain medical care or obtain care only when their condition is beyond treatment.[22]

Recommendation: Congress and the President must address the gap between qualifying for public assistance and being able to afford private health insurance. Specifically, Congress and the President must design and implement a plan that ensures all individuals, regardless of race, ethnicity, gender, or socioeconomic status, have financial access to quality health care.

Steps toward universal coverage might have to be made incrementally. One solution, at least in the short run, would be to make existing programs available on a wider scale, particularly for those who have qualified for public assistance in the past but, due to changes in welfare legislation, no longer qualify or are unaware that they are still eligible for benefits. For example, insurance coverage could be extended to the parents of children who are enrolled in the Children's Health Insurance Program, or medicaid could expand eligibility to individuals who have higher income levels but are still the working poor. The low-income uninsured should also be able to purchase subsidized medicaid coverage if they are not eligible for full coverage based on income. Another possible solution would be to encourage employers to provide insurance to all employees. Tax incentives based on the size of the firm, with small employers (including minority businesses and small family businesses) receiving a greater tax benefit, might enable firms to purchase insurance through the open market and would expand the option of employer-sponsored insurance to a larger portion of the work force, particularly low-wage workers who are employed in small companies or minority and family run businesses.

A long-term plan, however, is needed to stymie the growing uninsurance rate and to ultimately improve the health status of the Nation. Several recommendations have been made by advocacy groups and private organizations as to ways in which universal health insurance coverage can be achieved. The Commission recommends that Congress revisit this issue, because in the current system, health insurance coverage is inextricably linked to the ability to access health care. Congress and the President should allocate funds for an initiative specifically designed to identify solutions and to close the health care financing gap.

A health care financing initiative should pay deliberate attention to the poorest persons, especially because of their higher rates of disease and disability, and include a provision that services must be delivered by health care providers to all individuals without discrimination on the basis of ability to pay for care, or any other basis unrelated to the individual's need for the service.

There must be consideration of alternative forms of providing health insurance, other than relying on employer-based insurance, which does not result in universal coverage. One appropriate and effective strategy would be to emulate the current health care plan offered to Federal employees for those who are uninsured or underinsured. Public insurance recipients, including those currently relying on medicaid, should have choices in plan selection so that their individual needs can be met. Such choice would alleviate concerns that universal coverage would have a negative effect on the insurance market and would be devastating to the health industry. Government would identify several networks or health insurance providers that individuals could choose from. Plans would compete for market share and be required to meet standards for providing adequate coverage.

Individuals who choose to enroll in a government-assisted insurance plan would be given a variable tax credit based on need for the purchase of coverage. This plan should be made available to all individuals who do not have employer-sponsored insurance as well as for those who do, but choose not to use it. However, this tax credit must be generous enough to cover the current high cost of health insurance, with higher income limits for eligibility than have previously been used to determine eligibility for other forms of public assistance. To be effective in reducing the number of uninsured, this income-based tax credit would have to provide low-wage workers with a greater percentage of their income in tax credit than those at higher income levels. Rather than allocate a fixed credit across the board, credit would be based on need. Further, when assessing one's need, many factors

[22] *See* chap. 3, pp. 91–105.

besides income must be taken into consideration, such as existing health conditions, and the subsequent cost of care, number of dependents, expenses such as debts, and cost of living.

This type of program must also provide relief for those individuals who are underinsured—those who may have health insurance through an employer, but who still cannot afford high deductibles or the uncovered portions of health care. In these instances, it is necessary to include a provision for additional optional coverage that would make up the difference and would cover deductibles and uncovered health care to the same extent that government-sponsored insurance would. Tax credits for the purchase of this supplemental insurance would be less than that given to those enrolled in the government plan, but would have to be enough to cover the added insurance premiums.

In designing a plan for providing health care to low-income individuals, policymakers must take into consideration the fact that health insurance is often a low priority for those who struggle with limited resources. Program benefits must be easily obtainable, and the incentive must be worthwhile for participation rates to be inclusive of all who are uninsured.

Finding: In addition to the economic barriers shared with other racial and ethnic minorities, immigrants face unique barriers to obtaining public assistance for health care. Many in immigrant communities fear that if they receive medicaid or other public health benefits, they will be considered public charges, which will affect their immigration status. Although the use of public services alone is not grounds for exclusion, there is sufficient ambiguity in this area to prevent many immigrants from seeking public health benefits. The result is little or no use of either preventive or necessary medical care, resulting in poor health status. Thus, in the long run, more money will be spent on emergency care, on the spread of untreated infections and communicable diseases, and in the treatment of prolonged or aggravated conditions that could have been prevented had early health care been received.[23]

Recommendation: OCR regional offices must oversee coordination with immigrant communities and advocacy groups to ensure that any misinformation about eligibility for medicaid is corrected. Many immigrants do in fact qualify for public assistance, particularly children. It is also the responsibility of HCFA, as the agency within HHS that controls medicaid funds, and the State agencies that distribute them, to ensure that those who are eligible are aware of their status. HHS must also work in conjunction with the Immigration and Naturalization Service to develop clear policy guidance on immigration status and public assistance. This information must then be disseminated through immigrant community information networks.

The Effects of Welfare Reform on Health Care Financing

Finding: Welfare reform of 1996 had a significant effect on health care, especially medicaid. The changes to public assistance have caused much confusion among former public health insurance recipients as to eligibility standards. The new guidelines were intended to maintain access to medicaid eligibility, and in some States, make the qualifications more inclusive. However, some provisions of welfare reform have caused others to lose medicaid eligibility. The new law includes tightened eligibility criteria for coverage of disabled children under supplemental security income (although some of these children may qualify for medicaid under other criteria). With the passage of welfare reform legislation, lack of U.S. citizenship became an important factor, by limiting eligibility and access of noncitizens to public benefits. Before the 1996 welfare reform, legal immigrants were generally eligible for medicaid and other Federal benefits. Immigrants who entered the United States before the law's enactment may remain eligible for medicaid, but those who have arrived since are banned from receiving Federal assistance, including medicaid, for at least 5 years.

Women also face a disadvantage as a result of welfare reform, as they dominate the ranks of welfare recipients. In 1993, of the 5 million families receiving Aid to Families with Dependent Children (AFDC), 90 percent were headed by women. Many of those receiving other types of general assistance were also women. Attempts to convert medicaid to a block grant program with capped Federal funding levels and without automatic eligibility for prior AFDC recipients will have significant implications for poor

[23] *See* chap. 3, pp. 102–03.

women's access to medical care and will further jeopardize the health of their families.

In response to the changes in welfare legislation, OCR has produced draft guidelines for States and caseworkers outlining their responsibilities for ensuring that legal obligations under Federal civil rights laws are being met in the administration of public assistance and welfare services. These guidelines give examples of instances where potential civil rights violations may occur, however, none of the examples cited is from the health care context. They also fall short by failing to identify the potential civil rights impact welfare reform will have on minorities and women.[24]

Recommendation: Now that States have restructured public insurance programs in response to the Personal Responsibility and Work Opportunity Reconciliation Act of 1996 (PRWORA), OCR regional offices should be involved to ensure that adequate civil rights provisions have been included in the implementation of State health insurance programs. States have a fair amount of discretion on how they implement public assistance programs, but OCR must ensure uniform civil rights compliance, as mandated in Federal civil rights laws. For example, OCR should ensure that public insurance enrollment procedures do not exclude minorities because of discriminatory policies and other actions that result in a disparate impact on minorities, and that health care is not compromised by changes in health insurance coverage as mandated by welfare reform provisions. A State review board should be established, with participation from OCR regional staff, to assist in the revision of eligibility criteria and to monitor the implementation of public insurance programs from a civil rights perspective.

OCR needs to modify its draft welfare reform guidelines to include examples of civil rights violations in the health care context as they may occur under PRWORA. In addition, OCR should clearly identify how PRWORA will specifically and disparately affect health care for minorities and women, as a pertinent civil rights issue. OCR must work with HCFA to further develop and widely distribute user-friendly guidelines for recipients of public insurance, informing them not only of their eligibility, but also of their civil rights. These information guides must be translated into several languages to be of use to immigrants who have been particularly affected by welfare reform. Further, OCR must carefully monitor State agencies to ensure that those requiring public assistance to meet their health care needs are not subject to different treatment under welfare reform laws.

Health Research

Finding: Women and minorities traditionally have not been included in health research studies. Broad-based inclusion of women and minorities in clinical trials is a civil rights issue as well as a sociopolitical one. Relatively little information is available on genetic differences that affect the manifestations of certain illnesses and their treatments. Although the National Institutes of Health, the Centers for Disease Control, and the Food and Drug Administration have issued requirements in the past 6 years that women and minorities be included in clinical trials, it is unclear to what extent inclusion is monitored and enforced.

Many minorities are hesitant to participate in research studies and receive treatment because of the distrust created by earlier exploitation and discrimination. This, compounded with other barriers, including limited English proficiency, lack of transportation, inconvenient clinic hours, and potential for lost wages, not only make participating in trials a low priority but make participation an impossibility for many minorities. The misinformation resulting from research that lacks an understanding of minorities and women has potentially life-threatening ramifications. The lack of research contributes to a lack of knowledge about prevention and treatment procedures, leaving health care providers to rely on speculation and assumptions.[25]

Recommendation: HHS must take the lead in enforcing the mandated inclusion of females and minorities in health-related research, both as participants in and recipients of Federal funds for research. The Department must require its agencies to take strong and effective steps toward ensuring that minorities and women are adequately included in projects and programs. HHS should establish an interagency task force to review research proposals, projects,

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[24] *See* chap. 3, pp. 106–09.

[25] *See* chap. 3, pp. 109–17.

and clinical trials to make certain that minorities and women have been incorporated into such programs from the initial planning stages.

OCR staff should work closely with operating division staff to ensure that scientists are tracking the race, ethnicity, and gender of their participants. OCR could accomplish this by providing outreach to applicants and monitoring research studies to ensure that participants are diverse in race, ethnicity, and gender.

Researchers and scientists must make efforts to reach underrepresented communities, and reevaluate the scientific protocol so that it is congruent with the beliefs and practices of those communities. Making the trials more accessible by providing transportation and offering other medical care as compensation might serve as incentives for potential participants. Through its minority and women's health offices, HHS should promote and support outreach and education programs in minority-populated areas to enhance awareness of ongoing research projects and increase participation of women and minorities in clinical trials. These offices should establish liaisons with local organizations, schools and clinics, and individual researchers to disseminate information aimed at alleviating misgivings and misunderstandings about such projects.

Further, although there have been many important gains made in the research on women's and minorities' health, continued funding is critical in order to address additional questions, confirm what initial studies have found, and understand what those findings really mean. Many research areas must be explored to fully understand the complexities of health. Research is needed in biomedicine, health behavior, screening technology, alternative modes of health care financing, delivery of disease prevention information, and the policy implications of proposals surrounding women's and minorities' health concerns.

Chapter 4: Health Care Programs and Initiatives at the Federal, State, and Local Levels

Summary

Despite the overwhelming evidence of health disparities, and the lack of vigorous civil rights enforcement, there have been many initiatives that target the health concerns of women and minorities. Although the initiatives vary in scope and mission, they share a common set of goals, including producing health practitioners who are skilled in providing quality health care for women and minorities, developing researchers who understand the necessity of addressing the health concerns of women and minorities, and improving access to gender and race/ethnicity specific, culturally competent health services within a changing health system.

HHS has several departmentwide initiatives and programs designed to address minority and women's health disparities. Four initiatives have been decreed by Executive orders: the Historically Black Colleges and Universities Initiative, the Hispanic Agenda for Action, the Tribal Colleges and Universities Initiative, and the Asian American and Pacific Islander Initiative. These initiatives provide support for educational institutions so that they can improve their infrastructures to increase productivity for education and research on relevant minority health issues. Other departmental initiatives include Healthy People 2000 and 2010, and the President's Initiative to Eliminate Racial and Ethnic Disparities in Health, which aims to eliminate disparities among racial and ethnic groups by the year 2010.

These departmental initiatives are monitored in part through the coordination and oversight of the Office of Women's Health and the Office of Minority Health in the Office of Public Health and Science. The Office of Women's Health was established, as a result of pressure from women's advocates, to improve the health of American women of all ages, races, and ethnicities by advancing and coordinating a comprehensive women's health agenda. The Office of Minority Health was primarily established to ensure that issues related to minority health are integrated into the day-to-day operations of the HHS' operating divisions. However, while these two offices have significant interaction with each other, their effectiveness as peripheral enforcers of civil rights is limited by the lack of interaction with the Office for Civil Rights.

The operating divisions implement the multiple programs that directly target and affect minority communities. Most operating divisions have decided on their own to establish and fund women's and minority health offices; however, some, such as the Health Care Financing Administration, have chosen not to do so, but in-

stead to address these issues within specific programs. In response to the Commission's request for information, many of the operating divisions provided information about innovative and effective minority and women's initiatives. For example, many of the agencies within the National Institutes of Health sponsor workshops and conferences, provide training programs and technical assistance, and collaborate with minority and women's organizations to target minorities and women both as health care professionals and consumers.

Other operating divisions have designated individuals to initiate and track minority and women's health programs. These programs often result in interagency agreements with other HHS entities, particularly when addressing the departmentwide initiatives. The Health Resources and Services Administration has taken a more comprehensive approach, recognizing and addressing all facets of health care from education to service delivery to research; and women's and minorities' health issues have been integrated into HRSA's general functions. The Centers for Disease Control and Prevention and the Food and Drug Administration both fund research and education/outreach programs to address specific health concerns of minority and women populations and provide information on racial, ethnic, and gender differences in diseases and their treatments. The Substance Abuse and Mental Health Services Administration has done the same by focusing on how women and minorities are differentially affected by specific mental health illnesses and the effectiveness of subsequent care.

Many State health agencies, with the assistance of Federal funds, also have recognized the need to address the health care needs of traditionally underserved populations. For example, several States have created separate offices to address these issues. The responsibilities and authority of the offices vary, but they serve as cornerstones for oversight and implementation of State programs in much the same way that the offices of minority health and women's health do on the national level.

Initiatives at the State level include identifying disparities in health status, increasing access to care, and improving the level of health education and outreach in underserved communities. Most efforts at the State level appear to be in data collection and the production of group-specific health reports, often in conjunction with the missions of national initiatives. Other programs seek to reach specific communities, such as immigrants, whose health care needs are often neglected. Still others take disease-specific approaches to health issues, focusing on the differences in illness and health care utilization rates between groups.

Public and private medical schools and teaching hospitals across the country have taken a more localized grassroots approach to address the health care needs of specific communities and are engaging in programs to identify problems with and work toward solutions for the health care system. At this level, health care providers have recognized that initiatives extending beyond traditional medical care are necessary to address the needs of various communities. This has been accomplished through the development of diversity programs, assessment of community-specific health care needs, and development of programs that improve access and quality of care for women and minorities.

Looking at programs and initiatives at all levels—Federal, State, and local—allows for the development and replication of blueprints for programs that can remedy deficiencies in access to health care and that can be applied at a more global level. However, rather than relying on initiatives as remedies to existing problems, emphasis should be placed on the promotion of health and the prevention of inequality, which can be achieved through greater collaboration at the Federal, State, and local levels. Moreover, the current lack of interaction between the entities implementing these programs and civil rights experts limits the potential effect of even the most innovative programs.

Maximizing the Effectiveness of Health Care Initiatives

Finding: Many initiatives have been implemented that target the health concerns of women and minorities, but initiatives alone cannot narrow the gap in health care or eliminate health care disparities. Viewed in a civil rights context, these initiatives have the potential to work toward the elimination of disparities while improving the health status of women and minorities. However, several HHS entities, including many of the HHS operating divisions

and State and local health care organizations have little or no contact with OCR, and as a result, civil rights concerns are not integrated into their initiatives.[26]

Recommendation: Civil rights objectives should be integrated into all initiatives during initial planning stages. OCR should take a proactive approach in integrating civil rights concerns into all health care initiatives and not wait until discrimination has occurred to react to an issue. OCR also must be informed of operating division activities, including the production of reports and the development of pertinent initiatives. OCR should be more proactive in monitoring the implementation of all initiatives at the Federal, State, and local levels. OCR should provide guidance and training to ensure that civil rights laws are understood and followed by those receiving funds to implement health care programs. HHS should make it a top priority to also train Office of Minority Health and Office of Women's Health staff at headquarters, and all minority and women's health staff in the operating divisions, on their civil rights responsibilities.

Each women's health and minority health office in HHS should have a senior civil rights analyst on staff who would be responsible for overseeing civil rights implementation in the operating division projects and programs. The civil rights analyst should interact with OCR to provide feedback on how civil rights have been incorporated into current HHS projects. Minority and women's health offices and/or coordinators should provide monthly summaries of operating division reports to OCR.

In turn, OCR should appoint staff members responsible for keeping the civil rights analyst in each operating division minority health office and women's health office abreast of any changes in civil rights law and/or how existing civil rights laws are interpreted and reinterpreted in various health care contexts. This staff member should be aware of all reports and activities of these offices and should receive any summaries or monthly activities the operating divisions send to OCR. This staff member also should ensure the dissemination of these reports among OCR staff.

In addition, OCR should develop an interoffice working group to examine the relationship between civil rights enforcement and the work of operating division civil rights, minority health, and women's health offices. This working group should meet regularly to address civil rights issues and to assess the effect of civil rights enforcement efforts within the operating divisions. Any findings of this interoffice working group should be presented to the heads of OCR and the operating divisions.

Finding: Various governmental initiatives are designed to improve health care for women and minorities. Many are innovative and creative in their approaches to achieving this goal. For example, "Baby Bundles," a program established by the Texas Department of Health to address the need for prenatal care for minority and poor women, partners community volunteers with public health professionals to reduce the number of low-birthweight babies and lower the infant mortality rate. However, no matter how well-designed, health care initiatives will not be successful in their missions unless their goals transcend the programmatic level to become institutionalized in all aspects of health care service delivery and research.[27]

Recommendation: By placing an emphasis on the promotion of quality health care and the prevention of inequality rather than relying on initiatives as sole remedies to problems, HHS can better assure that minorities' and women's concerns become institutionalized in the Nation's health care system. However, until full integration occurs, initiatives and programs can remedy some existing inequalities. It is thus essential that all government agencies at the Federal, State, and local levels, as well as other health care related organizations, replicate the initiatives that work on a more universal level. HHS components, namely the operating divisions and OCR, need to examine State and local, public and private health care programs and research studies initiated outside the Department to keep abreast of health care concerns and issues both regionally and nationwide. Also, HHS should rely on electronic information in databases and on the Internet to help locate these programs.

Recognizing the initiatives on a more universal level would help HHS develop innovative and

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[26] *See* chap. 4, p. 118.

[27] *See* chap. 4, pp. 118, 175.

creative projects. Programs such as the Baby Bundles project in Texas should be implemented at the Federal level and all States should be encouraged to develop similar programs. HHS should include as many of these kinds of programs as possible in its Strategic Plan. In addition, HHS should require that OCR and the operating divisions implement them to formulate timely and effective health care improvement strategies and initiatives that can positively affect Americans who currently do not have adequate access to quality health care. HHS should call on OCR to assist the operating divisions by conducting proactive efforts, such as compliance reviews, to determine any underlying civil rights concerns that created the need for various initiatives.

Implementing Effective Programs: The Need for Adequate Funding and Creative Ideas to Energize Minority Health Offices

Finding: HHS allocates millions of dollars each year to ensure that the operating divisions are able to implement minority and women's health programs. However, the funds slated for minority and women's issues are small in comparison to the Department's total funds. For fiscal years 1998 and 1999, approximately 1 percent of HHS' total funds were designated for minority initiatives and programs. The amount has been increased for FY 2000 to approximately 2.5 percent. Women's programs and initiatives fare slightly better at approximately 13.5 percent of all HHS funds in fiscal years 1998 and 1999, and 14.2 percent projected for FY 2000. These very small budget allocations are one of the most significant problems hindering the development of strong, effective minority initiatives that have the potential of doing more than providing weak, stopgap measures to the enormous problems of poor health status and inaccessible health care.

There appears to be a strong reluctance to appropriately fund and promote programs that can assist minorities' efforts to gain equal access to quality health care services. Without adequate funding there is little chance that HHS can play a role in truly eliminating the wide gap in the quality of health care between minorities and nonminorities. The lack of funding for minority initiatives is yet another example of HHS' tendency to take a reactive rather than proactive approach to addressing disparities.[28]

Recommendation: The allocation of funds for minority and women's health programs should be more equitably distributed. The amount of funds distributed should be based on the size of the minority populations for whom the programs are targeted. In addition, HHS health care initiatives and programs for minorities should be funded at a level high enough for the Department to develop and design initiatives that can provide the earliest possible outreach, intervention, and prevention.

In addition, HHS minority initiatives and programs should target young people and continue to follow them through high school and into adulthood. Such programs should focus on nutritional needs of poor and minority students, health education that emphasizes prevention and willingness to seek medical treatment, and ensuring availability of medical facilities in areas and neighborhoods where a high proportion of racial/ethnic minorities reside.

In order to promote maximum effectiveness, these programs must be implemented almost entirely at the grassroots level. Federal employees at HHS should remain in the background, as silent partners. All of the actual activity, including a large portion of program development, should occur at the local level, where it can permeate the entire minority community. Efforts should be part of a comprehensive network that encompasses schools, community centers, local health care facilities—including clinics, nursing homes, managed care organizations, and child care centers—and local health care professionals.

All health care programs and initiatives should be designed in a culturally competent manner to address the needs of different racial/ethnic minorities. The programs also should have adequate funding to incorporate strong outreach and education components. This aspect of the program initiative should include an advertising campaign using a multimedia approach, such as posters, brochures, mailouts, and public service announcements on radio and television. It also should encompass onsite visits by medical and nutritional experts to primary and secondary schools. These visits should be part of

[28] *See* chap. 4, p. 119.

regularly scheduled "health care awareness" days, which would be much like "career days" except their entire focus would be on providing minority students with raised awareness and understanding of the importance of proactive, preventive, and vigilant efforts to maintain the best possible health status and to gain access to the highest quality health care services.

Collaboration Between OCR, Office of Women's Health, and Office of Minority Health

Finding: In recent years there has been increased collaboration between the Office of Women's Health (OWH) and the Office of Minority Health (OMH). For example, the OMH has assisted the OWH with the Centers of Excellence Program. This program provides funds to health care facilities to serve their communities, particularly with regard to women's and minorities' health issues. Currently, all awardees have been academic medical centers, but work is being done to include community-based facilities as well. Because there are many similar issues of concern for women and minorities, the OWH and OMH convene at headquarters for programmatic updates and to discuss new initiatives.[29]

Recommendation: Overall, HHS must work to establish strong cohesiveness throughout its many and varied offices, agencies, and other internal elements to implement initiatives focusing on women and minorities. To accomplish this, all HHS components must communicate with each other and share ideas in their efforts to implement programs. Because nearly 26 percent of all women are minorities, and half of all minorities are women, it is particularly important for offices of women's health and offices of minority health to work together closely. The health issues of minorities and women are often intertwined. OCR, OWH, OMH, and other staff should work together routinely to share information, keep abreast of issues and/or concerns, assess how these issues affect their missions, and provide feedback on how effective projects are being implemented. OCR needs to be involved in the planning and implementation of these initiatives, since their success can have a significant effect on OCR's civil rights compliance and enforcement activities.

State health agencies must also encourage interaction between women's and minority health offices. Those States that have already established these offices are in a prime position to implement concurrent projects and initiatives. Joint ventures will not only benefit a greater number of underserved individuals, but will make implementation of programs more economically feasible. Additionally, local minority and women's health agencies and advocacy groups should create alliances to address concerns that affect both communities. These organizations should work toward identifying programmatic deficiencies in State and Federal initiatives, and offer suggestions on how specific programs can address the needs of both women and minorities at the same time.

In addition, OCR should offer operating divisions and State and local health care organizations technical assistance and guidance on civil rights requirements applicable to their health care initiatives. This information should be communicated to local advocacy groups and research organizations that target minorities and women in their projects and activities. OCR should be included in the implementation of the initiatives and insist that the operating divisions and their recipients comply with the mandate to include these groups in HHS programs and initiatives. The Secretary of HHS should require that the operating divisions and OCR work together to show the relationship between civil rights enforcement organizations and the initiatives, and to ensure uniform compliance with civil rights concerns in the objectives of the initiatives.

Finding: OCR has very little or no contact with operating divisions, States, or local minority and women's health offices. There also has been no collaboration between the Office of Public Health and Science's Office of Women's Health and OCR. As a matter of fact, the director of OWH, until recently, was unaware of the function of OCR, nor did she know any of the employees or managerial officials employed in OCR. The women's health coordinator at the Health Care Financing Administration serves on departmental committees and meets with other HHS offices, but was not aware of OCR until she received information on the Commission's health care study. The director of the Office of Research on Women's Health within the National Insti-

[29] *See* chap. 4, pp. 119–22.

tutes of Health has not had any contact with OCR. In addition, OCR headquarters and regional offices do not have contact with State offices of minority health and women's health.[30]

Recommendation: Interaction with OCR should provide opportunities for addressing the health care issues of women and minorities. OCR must become more visible through networking, providing training and briefings, and reaching out to the operating divisions and other agencies within HHS. The link between the initiatives and OCR's role in civil rights enforcement should be understood by all affected HHS staff. OCR should take the leadership role on all departmental committees that address equality of access to health care for minorities and women. OCR staff should regularly interact with other HHS components involved with minority and women's initiatives. In addition, OCR should establish a liaison specifically to coordinate with all OMH and OWH offices, components within HHS, and State and local minority and women's health offices. OCR should develop a mechanism for communicating and sharing information with operating division coordinators who are responsible for overseeing the initiatives at the agency level.

OCR should distribute to the operating divisions and other components of HHS updated information with photographs and telephone numbers of each of its individual staff members so that operating division staff will be aware of who OCR is and what role the office plays in the enforcement of civil rights laws.

OCR, particularly the regional offices, should view State offices of minority health and women's health as valuable resources. In addition to collaborating with these offices to identify where potential civil rights violations occur in State policies, OCR regional offices should train office staff members on how to ensure that civil rights objectives are incorporated in all State health care programs. Further, OCR regional offices should interact on a regular basis with local organizations and advocacy groups who are more likely to be aware of actual civil rights violations as they occur. The civil rights process should be one of interaction among all entities: OCR headquarters, OCR regional offices, State women's health and minority health offices, and local health organizations and advocacy groups. The dynamics provided by the interaction among these groups will greatly assist OCR in meeting its goals.

Ensuring Minority and Women's Participation in Research Projects

Finding: The operating divisions control a large portion of HHS resources and implement multiple programs that directly target and affect minority communities in this country. One of the goals of the minority health office within each operating division is to ensure that issues related to minority health are integrated into the day-to-day operations of that operating division. However, the minority health office does not have any formal methods or policies by which it makes sure the operating division is incorporating minorities in research and other projects. Currently, the Centers for Disease Control and Prevention, the National Institutes of Health, and the Food and Drug Administration have individual inclusion policies for minorities and women in their funded research projects. However, there does not appear to be any mechanism for monitoring the inclusion of diverse subjects.[31]

Recommendation: The Secretary of HHS should implement a departmentwide policy mandating that each operating division incorporate minorities' and women's health concerns into all programs, particularly research projects. A departmentwide policy should include a number of provisions. First, it should require that women and minorities are appropriately included in research trials at numbers proportional to the rates in which they are affected by the issue being researched. Second, study populations must be inclusive of minority subgroups and adequate numbers of women of color. Finally, offices of minority health and women's health within the operating divisions should be held responsible for monitoring inclusion practices. Oversight of operating divisions that do not have offices of women's health and minority health should be the responsibility of OMH and OWH at the departmental level.

National Institutes of Health

Finding: The Office of Research on Minority Health (ORMH) and the Office of Research on

[30] *See* chap. 4, pp. 120, 124, 134, 170–86.

[31] *See* chap. 4, pp. 119–26.

Women's Health (ORWH) at the National Institutes of Health can develop ideas for programs relating to minorities and women and contribute to their support by providing guidance on strategies, but they cannot make grants for such programs. Grant-making authority resides within the offices of the heads of each of the institutes and centers that compose NIH. The director of NIH has stated very clearly that internal elements attached to the Office of the Director, such as ORMH and ORWH, may not compete with the institutes and centers for grants. In addition, the review committees within the institutes and centers make judgments as to the scientific merit of grants. The longstanding problem with this approach is that many minority institutions, for example, historically black colleges and universities and Hispanic-serving institutions, believe that they are not playing on a level field, either in terms of the composition of review committees or in terms of the universe of institutions against whom they are competing for funding support. However, the ability to fund projects is critical for the implementation of programs and initiatives. Without this ability, offices such as the ORMH and ORWH have relatively little control over program development.[32]

Recommendation: The director of NIH should not withhold grant-making authority because of concerns about competition with institutes and centers. Rather, grant-making authority should be based on programmatic needs as demonstrated by health care gaps.

The Office of the Director should establish a program review and grant-making component within ORMH. Allowing ORMH this authority would provide the office with the ability to implement ideas for improving health status and access to quality health care within the minority community. ORMH would not have to rely on the institutes to decide whether a grant proposal will be accepted or whether a recipient is meeting the goals set by the institutes and centers, goals that some have viewed as arbitrary and overly stringent. The institutes and centers may lack the expertise that the ORMH possesses to determine the relevance and importance of specific programs.

Finding: The lack of HHS oversight of minority health offices and the unwillingness to grant these offices more responsibilities reflect a reluctance to develop effective offices of minority health throughout HHS. NIH's ORMH is not representative of the majority of offices of minority health within HHS operating divisions, which do little more than act as liaison or coordinator between offices or conduct monitoring activities. NIH's ORMH plays a more central role in the development and implementation of NIH minority initiatives.

NIH's ORMH has an $80 million budget, $70 million of which is used for supporting programs, including many pilot programs. Through consultation, ORMH makes determinations about the level of minority involvement and the quality of efforts to improve minority health. For example, ORMH can identify gaps in health care research, approach the relevant NIH institute or center, and work collaboratively to pilot new initiatives addressing identified gaps. Based on an evaluation of the success of the program, it is anticipated that the relevant institutes and centers would take responsibility for the program, fiscally and administratively. ORMH is considering a model whereby institutes and centers would be asked to share in the initial funding of pilot programs.[33]

Recommendation: The active role and the level of responsibility of NIH's ORMH should become a model for other minority health offices in the operating divisions. Moreover, the Commission supports the Congressional Black Caucus Health Braintrust Initiative to develop strategies and legislative options for funding the Office of Minority Health and to elevate the Office of Research on Minority Health at NIH to a full-fledged center. Offices of minority health within HHS operating divisions should not be relegated to the minor role they play in HHS' agency initiatives or programs. While their coordination and monitoring roles are important, these offices should play a more central role in developing and implementing the overall mission of their respective operating divisions.

For example, these offices of minority health should take the lead in overseeing important initiatives on minority health, and they should also ensure all operating division initiatives and programs address major civil rights compliance issues and that they contain strong civil rights

[32] *See* chap. 4, pp. 135–38.

[33] *See* chap. 4, pp. 135–38.

components. In particular, these offices should work with OCR to develop initiatives on such civil rights compliance issues as racial discrimination in managed care organizations, racial segregation in nursing homes, and minority participation in medical school programs. In addition, the offices of minority health and OCR should ensure that operating division initiatives incorporate civil rights training programs and publicity campaigns on the responsibilities of health care providers under Federal law.

Further, the Secretary of HHS should provide ORMH with the funding necessary to accomplish the above described tasks. The policy and programmatic roles and the resources necessary to carry out those responsibilities should make offices of minority and women's health full partners with other operating division offices.

Finding: NIH's ORMH partners with the ORWH, the NIH institutes and centers, and other Federal agencies on initiatives targeted at minority-serving institutions for the purpose of increasing the private sector's role in strengthening institutional infrastructure, facilitating planning, and using new technologies to ensure the long-term viability of institutions serving African Americans, Hispanics, and other minorities. However, minority institutions have cited HHS evaluations of the success of these programs as problematic. For example, some historically black colleges and universities (HBCUs) have expressed concerns that the funds and time to complete projects have not been sufficient. Apparently, inappropriate benchmarks are used in assessing the cost of doing research at minority institutions. Historically, HBCUs have been at a much greater disadvantage, in terms of infrastructure, than majority institutions, and many of these HBCUs still lack adequate facilities. The minority institutions have asked that release time allocations and current funding levels be reassessed to improve the opportunity for successful research enterprises at these institutions.[34]

Recommendation: To ensure more effective outcomes from the research done at minority institutions, HHS should reassess the benchmarks used in determining the overall level of funding support, particularly in the area of time allocations (including both research and teaching) for faculty doing research at minority-serving institutions. Opportunities for the successful completion of biomedical research at these institutions would be increased if they were accompanied by an increased investment in capacity-building programs by NIH targeting minority institutions, an increased investment in programs that would allow nonresearch-intensive institutions to compete with their peers for research funding, and a more appropriate assessment of research costs at minority institutions. This or similar language should be incorporated into the implementation plans of the current Executive orders that relate to minority-serving institutions.

Finding: Since an institution's infrastructure often determines its ability to compete successfully for research dollars, inadequacies in infrastructure, including the quality or availability of laboratories and research facilities have presented a problem for a number of minority-serving academic institutions. Furthermore, in the past year, NIH has aided at least one HBCU (Howard University) in making sorely needed improvements in its infrastructure so as to prevent the loss of its accreditation. Even when the missions of minority institutions are similar to their majority counterparts, the resources available for infrastructure development are simply less, thus severely curtailing the ability of minority institutions to successfully compete for the same pool of research dollars.

OMHR has recommended one method for creating equal opportunity for minority-serving institutions. The model would establish programs for which only institutions recognized under the Executive orders would be eligible to compete. Fair competition would be ensured through the design and development of peer group-specific programs. Each peer group would apply to competitive, targeted programs that support the mission of the sponsoring agency, but that are also responsive to the needs, missions, and potential of the applicant institutions.[35]

Recommendation: The Commission supports ORMH's concept of leveling the playing field as it relates to the competition of minority institutions for research and research training dollars at NIH and other HHS operating divi-

[34] *See* chap. 4, pp. 136–38.

[35] *See* chap. 4, pp. 137–38.

sions. This concept appears to be based on a hybrid of the underlying concept of small business innovation research programs and the Department of Education's title III program models. The model would create bands or peer groupings of institutions that would compete for the dollars in innovative programs that are sensitive not only to the missions of the grant-awarding agencies, but also to the reality and needs of minority-serving institutions. Developing this model would send a message to racial and ethnic minority communities that the Federal Government, in particular HHS, recognizes the importance of empowering all of its populations to become full participants in efforts to improve their health. Members of minority populations should be assured that the Federal Government recognizes the role that all institutions of higher learning can play in alleviating health disparities and improving the overall health of Americans.

Finding: NIH funds several programs that provide opportunities for faculty at minority institutions to update and sharpen their research skills, enabling the institutions to become more competitive for grant support. The number of minority researchers in the scientific work force is already severely limited, and unfortunately individuals with outstanding research credentials often lose their competitive edge at minority institutions due to heavy teaching demands and less than adequate research infrastructure.[36]

Recommendation: NIH should develop innovative programs sensitive to smaller institutions, where resources and time are limited for research and related activities outside the classroom. Innovative programs should offer incentives to encourage minority and female faculty to remain active in the research enterprise. Incentives may include summer fellowships, sabbaticals, and adequate time for research activities during the academic year, as well as funding community-based research in which faculty members may become involved.

For example, NIH could develop a program of research fellowships for professors at minority institutions that would provide 6 months to a year of sabbatical leave during which time the grantee could do research in a chosen area of health care. The purpose of the program would be to strengthen the medical and research skills and credentials of the fellows as well as keep them active in research. The program would have to provide appropriate support and resources for the fellow to conduct research, for the minority-serving institution that is relieving a faculty member of teaching responsibilities, and for medical research institutions or government agencies to create opportunities for fellows to participate either in ongoing medical research studies or studies of their own creation.

Finding: NIH has not focused on minority students in kindergarten through grade 12 (K–12). It may be prudent to consider enhancing minority interests in biomedical and related research well ahead of the college undergraduate years. Currently, there is a modest collaborative K–12 program jointly funded by the National Science Foundation (NSF) and the ORMH that focuses on mathematics and engineering.[37]

Recommendation: The Commission's commends NSF and ORMH for developing a program for younger people who can benefit greatly from efforts to enhance their participation in mathematics and science. Expansion of this program to include the life sciences might help to solidify the interest of more minority students in biomedical research well ahead of their college undergraduate years. Early introduction of children to sciences, such as chemistry, often defines the level of success students will have in competing for entry into and the completion of graduate training programs. The development of interest in medical professions can begin in their early years and be nurtured throughout their academic careers.

Finding: Relatively little health status data are available on health concerns of the different members of the Asian American community, which often results in an inaccurate interpretation of health care issues. NIH is working with Asian American organizations to design the collection of the much needed data. A primary focus of this effort is the collection of data on Asian American subgroups, such as Chinese, Korean, Japanese, and Filipino Americans and Native Hawaiians. One project supported by OMH and the National Cancer Institute focuses on Asian

[36] *See* chap. 4, p. 138.

[37] *See* chap. 4, p. 138.

American and Pacific Islander women and cervical cancer.[38]

Recommendation: Efforts should be made to ensure that all Asian Americans understand the importance and potential uses of the health-related data to be collected, especially in terms of how the collection of these data will benefit them. This will alleviate negative feelings or misgivings about participating in data collection activities. Through its operating divisions and OCR, HHS should: (1) expand its outreach and education to the entire Asian American community about health care issues and their relevance and importance; (2) expand its data collection instruments to include those issues pertinent to the Asian American community; and (3) produce these instruments in a culturally sensitive manner and in multiple languages. The Department should consult with Asian American community organizations about such data collection efforts and instruments, use the organizations as conduits for transmitting data collection instruments, and get feedback on how the instruments could be improved and made more relevant to specific communities.

Finding: ORWH funds many projects to increase the recruitment and retention of women in biomedical careers; however, claims that programs targeted strictly to women are discriminatory have sometimes been prohibitive to program development. For example, during the development of a reentry program for women scientists who had career interruptions due to child or elder care or relocation to be with a spouse, the office was told it could not target women only, that the program would be considered discriminatory. ORWH overcame the barrier by also accepting men—the program has served 35 women and 3 men.[39]

Recommendation: OCR needs to provide more outreach and education to communities and agencies both inside and outside HHS. It would have been helpful to ORWH to have had knowledge of what constituted discriminatory actions before developing its reentry program. It is OCR's responsibility to ensure that *all* offices within HHS are familiar with civil rights laws. ORWH's failure to know that it was engaging in potentially discriminatory activity is a good example of why it is important for OCR to undertake proactive efforts to ensure such familiarity departmentwide. The ultimate goal is to try to ensure diversity without practicing exclusion.

Finding: Minority issues are primarily the purview of the Office of Research on Minority Health. ORWH staff, however, do collaborate with the HHS Office of Women's Health on particular activities that concern minority women. Although the various women's health offices address the health concerns and/or issues facing all women, their programs do not necessarily reach and target the health issues faced by minority women.[40]

Recommendation: The health issues of minority women should not solely be the purview of the ORMH. The Secretary of HHS should establish a division within the Office of Women's Health that focuses on health issues for women of color. Further, a staff member in each women's and minority health office throughout HHS should be designated to coordinate the efforts for addressing health concerns of minority women. These staff members should meet monthly to assess how minority women can be integrated into every initiative and program, and to determine what the role of each office will be in meeting this goal.

Health Care Financing Administration

Finding: Currently, the Health Care Financing Administration has no separate office of women's health. The chief medical officer in the Office of Strategic Planning is assigned to women's issues part time as the women's health coordinator. In 1997, in response to the departmental initiative on women's health issues, HCFA assigned her as its representative to carry out the women's health projects and initiatives. The women's health coordinator has no policy-making authority and sees her role as advisory. Currently, no other staff are assigned to the area, and the coordinator has no separate budget for activities. There are no plans to establish an office of women's health at HCFA. According to the women's health coordinator, the potential to enhance women's health issues at HCFA, through data analysis and research initiatives and projects, has been hampered by the lack of managerial support or commitment to include

[38] *See* chap. 4, p. 138.

[39] *See* chap. 4, pp. 140–41.

[40] *See* chap. 4, p. 141.

women's health issues as a top priority or to expand women's health perspectives at the agency.[41]

Recommendation: Coordination of women's health issues, in an effort to incorporate civil rights into all activities, should be mandatory for all operating divisions. However, the minorities' and women's health care initiatives at HCFA, and all operating divisions, must have the support of agency administrators and managers. Further, the role of the minority and women's health coordinators should be more than "advisory." The lack of a separate office should not preclude the women's health coordinator from playing an integral role in project development. If there is no separate office, the coordinators should have the resources to participate effectively as representatives and participants with other departmental and agency components, including OCR. The coordinators should have the status to carry out policies affecting their initiatives, and be members of policy and program committees.

Finding: In response to the departmental initiatives and Executive orders to enhance the participation of racial and ethnic minorities in Federal programs, HCFA formed the Minorities Beneficiaries Work Group in 1996, rather than establishing a central office for the implementation of these initiatives. As a result, the implementation of the initiatives at HCFA is fragmented and has been dispersed throughout regions. Until very recently, the initiatives lacked agency oversight and coordination. Although the HCFA administrator recently appointed a coordinator to oversee the implementation, the coordinator has no staff or resources. Different components of HCFA are still implementing the initiatives without guidance, supervision, or accountability.[42]

Recommendation: HCFA should establish a central minority health office with staff, resources, and authority to oversee, monitor, and coordinate the minority activities and projects that are implemented at the agency, as well as to establish policy on such activities. Until that happens, the current coordinator must receive civil rights training from OCR, and must be briefed on the status of the initiatives he or she is intended to oversee. The coordinator should also take the lead in coordinating activities of the Minorities Beneficiaries Work Group to ensure that HCFA's activities with regard to the departmental initiatives are implemented most effectively.

Finding: HCFA has a system for tracking data, particularly with respect to medicaid and medicare information, yet the data in this system are not used regularly to examine minority and women's health concerns. According to the women's health coordinator, there is a wealth of information and great potential for use of the data, but currently there is no indepth analysis of the data being collected. Any statistics provided on the use of health services by women are generated from HCFA's budget office.[43]

Recommendation: HCFA should assign staff to extrapolate social, economic, and health care related information on women and minorities from its data tracking system. The women's coordinator should be actively involved in the assessment of this data (including suggestions on what data should be analyzed for these groups) to formulate issues, initiatives, and projects for women and minorities. The budget office should only provide data as it pertains to how much of the budget is spent in various areas of health care. The women's coordinator should have complete access to and responsibility for all data sets.

Health Resources and Services Administration

Finding: The Health Resources and Services Administration's Office of Minority Health (HRSA/OMH) has the lead role in developing a coordinated HRSA response to the Executive order on tribal colleges and universities. HRSA/OMH is collaborating with bureaus and offices throughout HRSA to develop a 5-year plan with yearly progress reports, and to devise approaches to ensure that tribal postsecondary education institutions have increased accessibility to Federal resources on a continuous basis. Furthermore, to assure quality health care to underserved, vulnerable, and special needs populations of American Indians/Alaskan Natives, HRSA/OMH is developing and implementing HRSA's Action Plan for Tribal Consultation. The plan will provide a core mechanism

[41] *See* chap. 4, pp. 155–58.

[42] *See* chap. 4, pp. 155–56.

[43] *See* chap. 4, pp. 155–56.

and process for strengthening the operating division's relationship with Native American customers, and to devise a strategy to address their needs.[44]

Recommendation: The Commission supports HRSA's plans to identify and eliminate barriers and problems related to access to care. When holding conferences and other activities for the Native American community, HRSA should continue to seek input from Native Americans served at the national, State, and local levels. In addition, HRSA should provide technical assistance and enhance Internet links so that various tribes can improve their understanding of HRSA's programs and funding opportunities. HRSA should also continue to disseminate surveys to tribal groups to measure their satisfaction with HRSA's services, and to enhance the overall communication between the operating division and Native Americans.

Finding: Under the Asian American and Pacific Islander (AAPI) Initiative, HRSA/OMH was one of the first offices in HRSA to start efforts to meet the health care needs of this community. In developing the framework for the AAPI Initiative, a working group held more than 25 meetings nationwide to get input from Asians and Pacific Islanders. HRSA/OMH sponsored a national conference with Asian American and Pacific Islander leaders in March 1998 to develop an action plan, and developed a component of HRSA's implementation plan that included input from the conference.[45]

Recommendation: Other operating divisions should follow HRSA's example in initiating strategies for implementing the AAPI Initiative. HRSA's AAPI work group should continue to hold regular meetings with AAPI leaders to get additional feedback on areas of health care of concern to the AAPI community and to monitor changes in needs as the population diversifies. OCR should continue to provide regional technical assistance to State and local agencies in both urban and rural areas, particularly those areas with large Asian American populations. If necessary, HHS should provide OCR with more funding for additional staff and resources so that OCR can serve a larger segment of the AAPI community.

Substance Abuse and Mental Health Services Administration

Finding: In 1994 and 1995, the Substance Abuse and Mental Health Services Administration's organizational structure included an Office for Women's Services with an associate administrator for Women's Services who reported to the Office of the Administrator. However, currently SAMHSA does not have an office for women's health or director of women's issues.[46]

Recommendation: SAMHSA needs to reestablish an office of research on women's health to more effectively address, evaluate, and resolve specific substance abuse and mental health issues that affect women. SAMHSA should also establish an office that provides leadership and coordination for programs related to minority health.

Centers for Disease Control

Finding: The Centers for Disease Control (CDC) has amassed information on minority and women's health care issues. In 1994 the CDC released a report on chronic disease and its effect on the major racial and ethnic minority groups. The document summarizes national demographic and health data related to chronic diseases in minority populations, and serves as a resource on such diseases and associated behavioral risk factors (for example, smoking) found within these groups. The report includes discussions on public health implications of population diversity and growth, morbidity and life expectancy, as well as risk factors and preventive health practices affecting these groups.

However, monitoring the health of minorities and women is only part of CDC's mission. In accomplishing its broader mission, the CDC monitors health status and issues, detects and investigates health problems, conducts research to enhance prevention, develops and advocates health policies, implements prevention strategies, promotes healthy behaviors, fosters safe and healthy environments, and provides health leadership and training.[47] The CDC has established partnerships with State and local health departments, academic institutions, professional and community organizations, philanthropic foundations, school systems, churches and other

[44] *See* chap. 4, pp. 159–60.

[45] *See* chap. 4, pp. 161–62.

[46] *See* chap. 4, p. 163.

[47] *See* chap. 4, pp. 165–67.

local institutions, and industry and labor organizations to accomplish these objectives. For example, CDC's Public Health Leadership Institute is part of an ongoing initiative that develops leadership skills of public health officials at the Federal, State, and local levels.[48]

Recommendation: Women's and minority health issues should be included in all activities related to the achievement of CDC's mission. CDC should establish partnerships with minority- and female-oriented institutions, community groups, research and medical associations, foundations, and other health-related entities to disseminate its information on minorities and women. CDC should hold a series of forums at minority-serving colleges, universities, and medical schools so that faculty and students are better informed about health care issues affecting women and minorities.

State Initiatives

Finding: Many States have created separate offices to address minorities' and women's health. The responsibilities and authority of the offices vary, but they serve as cornerstones for oversight and implementation of programs. For example, the West Virginia Minority Health Program serves as a resource in assisting organizations, health care providers, government agencies, and minority communities in decreasing morbidity and mortality, increasing general wellness, and eliminating the disparities in health status and access to quality medical care. The Illinois Center for Minority Health Services coordinates a Minority Health Partnership that provides information and assistance on a wide range of health-related issues to improve the overall health of minority individuals, families, and communities. The State of Illinois has an Office of Women's Health that inventories all women's health programs in the State, identifies areas of potential collaboration, and examines social, economic, psychological, and physical barriers to better health for women.[49]

Recommendation: HHS, specifically OCR, needs to draw on what States are doing with respect to minority and women's health. The Department should use the information on State initiatives to develop technical assistance and guidance, identify barriers to health care for members of these groups, and initiate proactive measures that will ensure inclusion of all groups in plans and initiatives relative to health care. OCR should use the State offices as a liaison to reach more community projects. They might also be effective partners for OCR regional offices, which could benefit from their resources.

Finding: Most efforts at the State level appear to be in data collection and the production of reports on group-specific health issues. Almost all of the States that submitted materials included information about data-gathering efforts, and many States have issued reports on health concerns of minorities and women, including comprehensive analyses of health services and utilization rates, disease-specific data, and demographic compositions of geographical regions.

For example, the Washington State Department of Health has issued several reports and other documents on statewide initiatives affecting women and racial and ethnic populations. One report provided statistics on the health conditions of minorities in the State, analyzed how their health concerns were addressed, and served as a springboard for improving data collection and analysis efforts concerning the health care of minorities in general and some of the Hispanic and Asian American/Pacific Islander subgroups. Another report found that American Indians have limited health care resources and difficulty accessing available services. The report presented the State's plan for American Indian health care delivery and provided recommendations for improving American Indian health care in Washington State.

States have also issued reports in response to HHS initiatives, Healthy People 2000 and Healthy People 2010, and have established programs focusing on narrowing the disparities in health status of minorities. For instance, the State of Nebraska Department of Health, Office of Minority Health and Human Services, produced a report addressing access to care, health status, and risk factor prevalence for African Americans, Native Americans, Asian Americans, and Hispanics. Also, the report addresses women's health issues, broken down by racial

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[48] *See* chap. 4, pp. 165–66.

[49] *See* chap. 4, p. 170.

and ethnic group, to identify how women of color are affected differently.[50]

Recommendation: The Commission commends States for producing their versions of the Healthy People reports. State reports detailing the health status and concerns of women, minorities and their subgroups are essential for highlighting areas where health and health care disparities exist and where intervention is most needed. All States should continue to produce reports on the health status of minorities and women. State efforts should not end with reports on health status. They also should examine disparities in health care delivery for minorities and women, identify barriers to equal access, and propose ways to overcome such barriers.

HHS operating divisions and OCR headquarters and regional staff should form liaisons with State and local officials, institutions, community organizations, research and medical associations, foundations, and other health-related entities to obtain their information on the health status of minorities and women and disparities in health care delivery, as well as proposed solutions. OCR and operating divisions could then use these reports to assess which States are not doing enough to eliminate disparities in access and could identify the programs or solutions that have worked well so that they can be publicized and implemented elsewhere.

Further, the operating divisions should review the recommendations for improving the health care of Native Americans that were proposed by the Washington State Department of Health, and implement programs and initiatives that will address those recommendations. OCR should also review the recommendations to better understand the areas in which more technical assistance is needed and can be provided to combat the disparities in health care for all minorities and women.

Finding: Immigrants and refugees are among the most difficult to reach for health care. A few States administer programs to provide health care specifically for these populations. For instance, the Idaho Department of Health and Welfare has established the Migrant and Seasonal Farm Worker Outreach Project to meet the needs of the estimated 119,000 migrant and seasonal farmworkers in Idaho. The program uses the services of the Idaho Primary Care Association, an organization of nonprofit health centers offering preventive and primary health care services to medically underserved areas of Idaho. Although the Community and Migrant Health Centers deliver health care services to these populations, the State recognizes that there are still gaps in access to primary health services due to the population's frequent travel, isolated housing, social and cultural differences, and transportation difficulties. The outreach project, therefore, includes activities to reduce these barriers to care, assist in recruiting clients, provide health promotion and education, and facilitate health services and coordinated care through referral and followup.[51]

Recommendation: HHS should do intensive outreach and education in areas with a large migrant population to help them understand health care services and initiatives that can improve their lives. HHS should work with State and local agencies that are administering health programs for these populations. The Department should use its networking information to channel resources and target projects for these groups.

State health agencies should be encouraged to replicate migrant and seasonal worker health programs. The Federal Government should allocate additional funds for health services, outreach, and education in regions where these populations reside. State health agencies also should partner with local health clinics and other providers to establish a network of care for migrant workers so that all of their health needs can be met, including preventive care, immunizations, illness screenings, dental care, and nutritional guidance. Health programs should also be developed specifically for children of migrant workers.

Finding: Many education and outreach programs include minorities and women as active participants in health care. For example, from 1996 to 1998, the Rhode Island Department of Health's Office of Minority Health and its Minority Health Advisory Committee sponsored a series of community forums targeting each of the major racial and ethnic minority groups to give consumers an opportunity to express their concerns and needs regarding health care. The

[50] *See* chap. 4, p. 170.

[51] *See* chap. 4, pp. 175–76.

State held eight community forums focusing on priority areas and barriers relating to health care for members of these groups. In 1998 the Department released a report on the community forums, which culminated in a minority health plan for the State.[52]

Recommendation: For outreach efforts to be more effective, and for health providers to better serve consumers, traditionally underserved communities must be involved in outreach planning and development and be given the opportunity to voice their health concerns. HHS, including the operating divisions, States, and health providers must involve minorities and women in advisory groups or other boards that plan the service delivery of health care. In addition, OCR should be involved with such groups in designing health service delivery plans to ensure that such plans are developed and implemented in a nondiscriminatory manner.

Finding: Many programs underway at the local level have the potential to vastly improve both health care delivery and the health status of underserved populations, if adopted more universally. The challenge of inclusive health care at the local level can be viewed as three phases: diversity programs for health care providers so they will understand what it means to provide culturally competent health care, assessment of community-specific health care needs, and development of targeted programs that improve the access and quality of care for the underserved.

Assessing the needs of a specific community is necessary if initiatives at the community level are to be successful. For example, the Greenville Hospital System in Greenville, South Carolina, did a study that aimed to identify health issues of particular concern to Hispanics in the area. After conducting surveys, focus groups, and discussions with health care providers, the researchers were able to produce several recommendations for how to best approach the needs of the growing Hispanic community. Researchers inquired into health care use patterns, barriers to care, and preferences for health care delivery of Hispanics in the area. They then assessed current providers to identify shortfalls.[53]

[52] *See* chap. 4, p. 177.

[53] *See* chap. 4, p. 181.

Recommendation: HHS needs to become more aware of initiatives and programs that are being implemented at all levels and by all types of institutions. Tactics to be replicated include increasing the cultural competency of health care providers and patients so that each has accurate expectations of the other, focusing on community-based facilities with hours and payment options appropriate for low-income workers, recruiting staff who speak languages prevalent in the area and improving communication abilities of existing staff, and using grassroots methods to reach minority communities.

Finding: The initiatives being implemented at the local level vary in scope, intent, and outcomes, but they share the common theme of integrating health services to address the needs of underserved populations and improve access to care. For example, the University of Arizona Rural Health Office has partnered with local tribes to develop needed health programs. The office has worked with the Tohono O'odham Tribe to develop, implement, and manage a professional education and training program for tribal members who will staff a 60-bed nursing home facility being constructed on a reservation. In addition, in 1997 the Rural Health Office began working with the Hopi Tribe to develop a health careers education program. Tribal members are being trained to staff a new Hopi ambulatory care facility. In 1998 Northern Arizona University received a grant from the Howard Hughes Medical Institute for science education, including support for teaching assistants and laboratory equipment to deliver health-related coursework to the Hopi Reservation high school via distance-learning technology.[54]

Recommendation: Through innovation, reassessment of funds, and creative use of available resources, many of these sample initiatives and programs can be replicated, resulting in a broader effect. Programs of this nature could become part of the Tribal Colleges and Universities (TCU) Initiative and should include all Native American tribes. Not only should TCUs be given funds to implement health care programs, but majority institutions in areas populated by Native American communities should be given funds to institute clinics and assist with the development of health services. The partnership

[54] *See* chap. 4, p. 182.

between the TCU and the majority institution would be mutually beneficial. Majority institutions can offer greater resources and often have a more advanced infrastructure to develop the health service, while the TCU can provide knowledge about the specific needs of the community and educate providers about giving culturally competent care.

Finding: State and local providers have found several innovative and effective uses of resources to improve access to care for the medically underserved. In Jackson, Mississippi, a deserted shopping mall was converted into the Jackson Medical Mall, with the University of Mississippi Medical Center as the anchor tenant. The facility provides a full range of care, and the Mississippi Department of Health has established clinics in the mall for other care. The mall serves as a one-stop location for comprehensive medical needs. Most of the persons served are medically indigent or receive medicaid.[55]

The Oregon Health Sciences University (OHSU) established a Center for Women's Health that integrates health care services and gender-related research, and also trains health care personnel. The unique aspect of the center is that its focus is not limited to the traditional areas of women's health care, such as obstetrics/gynecology, but includes nutrition and most medical specialties. OHSU also has an Indochinese Psychiatric Clinic that provides specialized services to Southeast Asian refugees. Additionally, OHSU coordinates the Screening Kids Informing Parents Program, which sends faculty and students into community centers and schools where they provide free health care assessments to inner-city children.[56]

Recommendation: Community resources such as schools, hospitals, and malls should be used to administer health care programs and services, particularly in underserved communities where outreach and education can be enhanced through these facilities. State and local health agencies should establish programs where federally funded network centers could be established to serve as neighborhood-based access points for health care. These neighborhood networks can then develop a plan for providing necessary care and offer more personalized health services.

Many outstanding programs have been initiated at the State or local levels, and they could be replicated at the Federal level, such as the Children's Health Place, a free pediatric health clinic located in a government-subsidized housing development that is home to a below poverty level population of African Americans, Hispanic Americans, and Asian Americans; and the Center for Minority Based Clinical Research which provides access to clinical trials to minority patients within the Duke Health System as well as training and career opportunities for minority investigators.

HHS must be committed to increasing and improving programs and services provided to minorities and women. HHS' offices of minority health and women's health should work together, and with OCR, to identify the many programs that have improved access to health care for the medically underserved. Then HHS should coordinate a system through which other facilities are funded to replicate such programs.

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[55] *See* chap. 4, pp. 182–83.

[56] *See* chap. 4, pp. 183–84.

Statement of Chairperson Mary Frances Berry and Vice Chairperson Cruz Reynoso

As major changes unfold in the manner in which health care services are delivered and financed, this report provides a unique and valuable contribution to the national debate and focus on this issue. The report documents the vast disparities in access to quality health care among U.S. populations and calls for a major national commitment to identify and address the underlying causes of the disparity and the subsequent reconciliation of this health care crisis. The demographic changes that will occur in this country over the next decade magnify the importance of the report's findings and recommendations and the urgent need for cooperation among Federal, State, and local governments, as well as private organizations.

Recognizing the importance of health care as it relates to our success and productivity as a nation, the Commission has consistently requested increases in funding for the U.S. Department of Health and Human Services' Office for Civil Rights. In furtherance of these requests, this report provides detailed information and guidance to OCR on crucial topics, such as closure of the health care financing gap, inclusion of people of color and women in health-related research, the acknowledgment of community-specific health needs, and the promotion of increased health care access for the underserved. The implementation of these recommendations will produce a meaningful improvement in the lives of many Americans who now disproportionately suffer from the burden of disease and disability.

Dissenting Statement by Commissioner Carl A. Anderson and Commissioner Russell G. Redenbaugh

The Commission's report on *The Health Care Challenge* is really two reports. First, it is an assessment of the enforcement of Federal laws by the U.S. Department of Health and Human Services (HHS) and its Office for Civil Rights (OCR). Second, it is an attempt to diagnose the chief ills of our health care system and to prescribe possible ways for addressing them. The report does a thorough job on the enforcement side of the issue; it clearly demonstrates the need for much-improved enforcement by HHS/OCR. The problem is on the prescriptive side, to the extent the report goes way beyond enforcement to advocate not only a whole new bureaucracy, but a national strategy to achieve a "leveling" in health care delivery, research, and financing. While we support much of what is in the report about the failures of Federal civil rights enforcement, the report is a thinly-veiled endorsement of universal health care, and advocates policies to achieve specific outcomes where market failures have not been demonstrated. That is why we decided, with reluctance, to vote against the report and that is the reason for this dissent.

Because the draft report we received is almost a thousand pages long, we cannot possibly address, in a brief dissent, all of our concerns. Some of the major problems we have identified include the following:

Invalid Assumption about the Nature of the Problem

Since the report was unable to prove "disparate treatment" (or "intentional discrimination"), it centers its discussion on the "disparate impact" theory, which is defined as "unintentional discrimination" that occurs "when a facially neutral policy operates in a way that affects a protected class of citizens disproportionately." The central theme is that everyone is entitled to the *same* "type, quantity, and quality" of health care services. The report considers "disparate impact" (for example, the fact that minorities may be less likely to have private insurance) to be the same as discrimination and, hence, remediable through civil rights legislation. This is a profound flaw. It will lead to more bureaucracy, more regulations and more wasted resources, but not "more health."

The Meaning of Health Disparities

The report is instructive in noting a number of disparities in areas such as life expectancy, mortality rates, disease prevalence rates, health care service utilization, availability of insurance, etc. These disparities are real, but their meaning is misinterpreted. For the most part they are a function of compromised access to care (reflecting private and public insurance coverage patterns) as well as lifestyle issues (e.g., drug use, sexual behavior, diet, smoking, etc.). Except in the obvious case of language barriers, they are not due to a lack of "cultural competence" or physicians' inability to communicate with patients of another race or ethnicity, nor is there evidence of physicians' failing to offer procedures to minorities because they are minorities.

The report tends to sweep away the problem of poverty and the impact it has on health care. Although the report (in volume I, chapter 2) does explain some of the socioeconomic factors influencing health care (education, income, and occupation), it fails to clearly identify the extent to which those factors (particularly poverty) explain differences in health care outcomes. In other words, is there a way to explain or identify health differences holding income constant? That is the important question the report has chosen not to address. The report concludes that since socioeconomic factors alone cannot account for all of the disparities, there must be "other factors" at work, i.e., discrimination and bias. Just to say that there may be "other factors" but that these are difficult to prove is not enough.

Cultural Competence

The "cultural competence" doctrine is a dangerous distraction from the real challenges we face with health care today. It is dangerous because it stresses identity politics over patient care and would substitute group-based generalizations for individual evaluations. It assumes that doctors (because of either a "conscious" or

"unconscious" bias) cannot communicate effectively with their patients who are "culturally different" or of another race and that this leads to fewer procedures which, in turn, leads to more illness among minorities.

There is no evidence, however, that race is a major determinant of how patients select their doctors, nor is there any reliable evidence or studies showing that anything but language compatibility really matters. It is true that doctors need to know a patient's background and local practices of diet, home remedies, etc., as they affect the patient's health, but doctors can do this with a relatively brief review of medical anthropology and by working with the patients themselves. In contrast, the measures outlined in this report would have doctors spend more energy separating patients into groups than treating them.

Nature of the Evidence

In going beyond civil rights to build a case for health care reform, the report relies heavily on law review articles and personal interviews with selected civil rights attorneys. Although some articles from reputable medical journals are also used, often the same ones are cited over and over. Studies are often cited indirectly, through a second-hand source. Very few physicians were interviewed, and almost no MDs are cited in the research. In some sections (particularly those dealing with affirmative action and research grants), the data are either nonexistent or out of date. Finally, the language of the report is in many instances overwrought and, frankly, inflammatory: for example, the "epidemic" of health care discrimination against women and minorities, the bias "infecting" our Nation's health care system, the "fabric of oppression" which is "ingrained in the lives of women of color," the "abominable" state of staff training within HHS/OCR, and HHS Secretary Donna Shalala's "timid and ineffectual" leadership of civil rights enforcement within the Department.

Another specific example of hyperbole and the lack of rigor in the statistical analysis can be found in the report's recommendation that HHS "mandate" the awarding of grants based on the proportion of women applying. The claim is that women researchers receive 21.5 percent of all NIH research grants and that this is a "blatant civil rights violation." There are several problems with this finding. First, the datum is old (from a report that collated information from 1981 to 1992). Second, without a denominator, it is meaningless. One has to know the percentage of the applicant pool that comprised women. Even if that were known, however, that in itself would be insufficient to claim bias since, after all, there should be no expectation that grants be awarded in proportion to the percentage of women who apply. They should be judged on their merits, like all grant applicants.

According to more recent information from NIH (covering 1992–1998), the gap in recipients of grants has narrowed, though this too must remain a qualified conclusion since as many as one-fifth of applicants in a given year were not identified by gender. But in 1993, the year in which only 3.5 percent were of "unknown" gender, 18 percent of the women who applied were awarded grants and 17 percent of the male applicants received grants. Thus, this does not appear to provide evidence of "blatant discrimination."

Erroneous Claims

*Women doctors "pigeonholed"?** —The report frequently asserts that women have been "pigeonholed" into lower status medical professions like pediatrics and psychiatry. There is no basis in fact for this claim, and the report fails to explore the extent to which women today may prefer some jobs over others because of family considerations or other personal choices. Further, recent studies show that women are also choosing to specialize in obstetrics and gynecology, a surgical subspecialty, in record numbers, to the point that some complain that male residents have trouble finding jobs. Since this specialty has the highest malpractice insurance premiums (and thus the greatest liability), the increasing number of women specializing in OB–GYN constitutes one of the most impressive signs of the advances women have made in various medical fields.

Women left out of research?—One of the chief complaints of this report is that "women have traditionally been ignored as subjects for clinical trials in medical research." (See volume I, chapter 3.) The evidence presented by other studies,

* When we submitted our dissent, the word used was "pigeonholed." It has since been changed to "steered." Our concern remains, notwithstanding the change.

however, shows that not only have women long been represented in medical research, but sometimes (e.g., in the case of clinical trials on HIV/AIDS) they have been overrepresented. Writing in *The Public Interest* (number 130, Winter 1998), Dr. Sally Satel points to data compiled by the Office of Research on Women's Health at the NIH which show that "women represented 52 percent of the more than one-million participants in NIH-funded research in 1994 (the most recent statistics)." Dr. Satel further notes that "[a]s early as 1979, according to NIH, 268 of the 293 active clinical trials involved males and females; of the remainder, 13 were all-female, 12 all-male."

The way the report frames its discussion on gender discrimination is important because it is illustrative of the way the report frequently tends to make a claim, based on the views of "at least one commentator," without backing it up with additional sources or factoring in any views on the other side of an issue. As a result, there is a constant thread of one-sidedness running throughout the report: "At least one commentator has suggested that the failure to use female test subjects in federally assisted research is a violation of title IX . . . a commentator writing on research and women's health reported studies that have found women patients may be more likely to follow through in obtaining tests suggested by women physicians because they are more comfortable discussing issues of concern with female physicians . . . as one commentator [the same one cited in the previous case] has noted, '[p]hysicians who are women or persons of color improve the availability and quality of health care. . . .'"

The analysis of women's participation in health care research studies is but one example of the report's proclivity toward generalization and the continual reliance on just one or two sources to build an argument (in this case, the "presence of significant barriers" to women's participation in such studies), which could easily be refuted by an equal number of "commentators." This is not to say that no problems exist, but only that we should not diminish the urgent need to address the special health challenges women face by confusing the need for additional research with the false notion that women are second-class subjects in clinical trials.

Failure of Affirmative Action?—In a lengthy discussion of minority recruitment in medical school admissions (volume II, chapter 3), the report justifies a call for broadening affirmative action by emphasizing that "a lack of minority doctors may result in limited access to health care for minority patients." It seems to take the position that affirmative action has not worked (to the extent that the proportion of minorities in medicine is still not high enough) and, thus, that increased affirmative action efforts are needed.

The report claims that the problem lies with the "current hostility of the Federal judiciary toward affirmative action policies in the professional school context." It criticizes the Supreme Court for narrowing the permissibility of affirmative action policies under the Constitution, calling this a "persistent yet baffling denial of the social, economic, and historical realities depriving our medical profession of minority physicians. . . ." It does not address the larger problem of why admissions gaps persist despite race-based advantages or why minority students continue to repeat the first year of medical school far more often than white students.

According to a 1994 report by the Institute of Medicine (*Balancing the Scales of Opportunity: Ensuring Racial and Ethnic Diversity in the Health Professions*), "under a mandate to increase the percentage of minority students," medical school admissions committees admit underrepresented minorities (URMs) with lower Medical College Admissions Test scores and lower grade point averages than their white counterparts. The American Association of Medical Colleges (AAMC) has documented that the acceptance rate for URMs have long been higher than for white applicants with similar qualifications. In 1979 a URM with high grades and board scores had a 90 percent chance of being admitted to medical school while a white applicant with comparable qualifications had a 62 percent chance. By 1991, the last year for which the AAMC has data, the qualified URM had a slightly better than 90 percent chance of admission while his white counterpart had a 75 percent likelihood of admission. Data compiled in 1998 by UC Davis Medical School, UCLA, and UCSF show that in California, even after the passage of Proposition 209, minority applicants were two to three times as likely to be admitted to medical school as whites and Asians with con-

siderably higher grades. Despite these race-based advantages in admission, the Commission's report maintains that "OCR has an important role to play in efforts to ensure more minority physicians in the medical profession" and stresses that OCR should "develop some form of policy guidance for medical schools to address this issue."

It is interesting to look at the results of a recent AAMC study, cited in our report, relating the underrepresentation of minorities in health professions to two factors: "(1) a scarcity of minorities who are interested in the health professions, and (2) the relatively small number of minority students who have the academic qualifications needed to pursue medical study." These findings are important because they underscore that what is needed is not more affirmative action but, rather, real initiatives for increasing the qualified pool of medical school applicants. That means remedial action at the elementary, secondary, and postsecondary levels of education, not government pressure on medical schools to increase the applicant pool by lowering standards.

Conclusion

The report is an important one insofar as it relates to the enforcement efforts of HHS/OCR. What we are unable to support are those findings and recommendations—in particular, the creation of a "new agency," the implementation of "new, comprehensive civil rights legislation," and broader, federally enforced affirmative action mandates—which go far beyond current enforcement issues to advocate an unprecedented intrusion by the Federal Government into the Nation's health care delivery system. This is not the right prescription for addressing the deficiencies of our health care system or for righting the wrongs of racism and discrimination in this country.

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