Articles

Unfinished Agenda: The Need for Civil Rights Litigation to Address Race Discrimination and Inequalities in Health Care Delivery

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I. Introduction

From Central Harlem to rural Alabama, poor communities of color are exposed to great health hazards and experience high incidences of many chronic and acute health conditions, but have access to relatively few health services. The consequences are devastating: high rates of infant mortality and morbidity due to childhood asthma, delayed care, and, ultimately, shorter life spans. This article argues that civil rights litigation could play a vital role in battling continuing patterns of discrimination in the provision of health care and the lack of access to care experienced by many low-income African Americans. Moreover, the current transformation of health care financing and delivery systems presents unique opportunities for intervention and legal challenge now, before historical practices replicate themselves and become entrenched in the new health care industry.

In the campaign for greater equity in the financing and provision of health care services, is there a need for litigation? What role would litigation play? Before reaching these questions, this article will first outline the need for civil rights enforcement in the health care sector. Disparities in access to health care are centuries old but continue to threaten quality and longevity of life for many African Americans. Further, virtually unchecked patterns of discrimination on the basis of race and ethnicity by medical personnel and facilities send a strong message about how we, as a society, value the lives of poor people of color. A mother who

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cannot find a pediatrician in the neighborhood to examine her child,[1] the person living with HIV/AIDS who cannot afford costly medication,[2] and the patient on a hospital's public ward who learns to shut off his own IV because the bag is empty and no hospital personnel will respond to his calls,[3] each understands the meaning of the message. The disparities are all the more amoral in a society that spends fourteen percent of its gross domestic product on health care, the majority of which is paid for by the public purse.[4]

Next, the article will turn to a historical perspective of legal advocacy and civil rights enforcement in the distribution of the health care services. Although civil rights advocacy in the health care area has been limited, in comparison to advocacy concerning discrimination in the areas of employment, housing and education, health care cases and advocacy have made a difference. Litigation puts issues on the table that are otherwise neglected. Although civil rights litigators have some key allies

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[1] *See, e.g.*, CHRISTEL BRELLOCHS ET AL., BUILDING PRIMARY HEALTH CARE IN NEW YORK CITY'S LOW-INCOME COMMUNITIES (1990) (documenting the dearth of primary care providers in low-income communities in New York in the pre-managed-care era); JANET D. PERLOFF & JAMES W. FOSSETT, STAFFING MEDICAID MANAGED CARE: PHYSICIAN SUPPLY AND NETWORK CAPACITY IN NEW YORK CITY (1996) (finding continued shortages of primary care physicians in very poor New York City neighborhoods).

[2] Enacted in 1990, the Ryan White Comprehensive AIDS Resource Emergency Act (CARE), Public Law 101-381, provides funding to cover some but not all of the costs of care for persons living with HIV/AIDS who cannot otherwise afford health services. As one recent study of the Ryan White AIDS Drug Assistance Program (ADAP) reported, a number of states across the country have lists of individuals eligible for the program but who must wait weeks or months for assistance. In addition, the increasing cost of the program has led to state policies restricting financial and medical eligibility criteria, a reduction in the number of covered drugs, and limits on the number of medications each beneficiary may receive. Robert J. Buchanan and Scott R. Smith, *State Implementation of the AIDS Drug Assistance Programs*, 19 HEALTH CARE FINANCING REV. 39 (1998); *see also* V. Shane et al., *Impact of Cost Saving Strategies for Access to Pharmaceuticals by Women and Minorities*, 12 INT. CONF. AIDS 986 (1998) (abstract no. 44253).

A disproportionate number of individuals living with and dying from AIDS are African American or Latino. Of the 612,078 estimated AIDS cases reported in the United States through June, 1997, 216,980 (or 35.4%) were Black (not Hispanic); 109,252 (17.8%) Hispanic; 4,370 (.7%) Asian/Pacific Islander; and 1,677 (.3%) American Indian/Alaskan Native. Centers for Disease Control and Prevention, 9 *HIV/AIDS Surveillance Report*, at 13 (1997) (Table 8: AIDS Cases by Sex, Age at Diagnosis, and Race/Ethnicity, Reported Through June, 1997, United States). By contrast, approximately 12% of persons counted in the 1990 U.S. Census were African American (not Hispanic), 9% Hispanic, 3% Asian/Pacific Islander, and 1% American Indian/Alaskan Native. U.S. Census Data (Database C90STF1C) (1990 Census) (Mar. 19, 1999) http://venus.census.gov/cdrom/lookup/921879441. More than half of the pediatric AIDS cases reported (4,818 of 8,280) through 1998 were Black as well. Centers for Disease Control and Prevention, 10 *HIV/AIDS Surveillance Report*, at 22 (1998) (Table 15: "Pediatric AIDS Cases by Exposure Category and Race/Ethnicity, Reported Through June 1998, United States").

[3] Marianne L. Engelman 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*, 60 BROOK. L. REV. 239, 247 (1994).

[4] Altman & Wallack, *Health Care Spending: Can the United States Control It?*, in STRATEGIC CHOICES FOR A CHANGING HEALTH CARE SYSTEM 3 (Altman & Reinhardt eds., 1996). According to the U.S. Bureau of the Census, total national health expenditures topped one trillion dollars in 1996. "Health Statistics," U.S. Census *at* http://www.census.gov/statab/www/part3.html (last visited Jan. 19, 1998).

(including, most notably, the National Health Law Program, as well as lawyers from legal service organizations and the private bar, and many national and community based organizations), there is no organized civil rights health care bar to carry the ball.

Lastly, the discussion will focus on areas for litigation and advocacy, suggesting three possible priorities, specifically:

1. Administrative advocacy to build mechanisms for civil rights enforcement;

2. Impact litigation to challenge redlining and other discriminatory practices engaged in by managed care organizations;

3. The development of new models of litigation to create and sustain medical infrastructure in underserved areas.

By way of qualification, it should be noted that this article does not provide full treatment of the legal grounds for each area of potential litigation. Readers interested in more discussion of specific legal claims can avail themselves of materials and analyses available elsewhere.[5]

II. Racial Disparities in the Distribution of Health Services and the Need for Civil Rights Enforcement

In the early 1990s, civil rights advocates, health care researchers, medical professionals, and representatives from an array of government agencies, community based organizations, and law schools gathered to explore access to health care as a civil rights issue and to chart a course for litigation and activism. The conference was co-sponsored by the NAACP Legal Defense & Educational Fund, Inc. (LDF), the School of Hygiene and Public Health at The Johns Hopkins University, and the Institute on Health Care for the Poor and Underserved at Meharry Medical College. In the years since the conference, discussion of national health care reform has come and gone, and the growth of managed care has dramatically

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[5] *See, e.g.*, NAACP LEGAL DEFENSE & EDUCATIONAL FUND, INC., INEQUITY IN THE DISTRIBUTION OF HEALTH CARE: CLOSING THE GAP – A REPORT ON THE ROLE OF LITIGATION (1992). [hereinafter LDF Report]; Barbara A. Noah, *Racial Disparities in the Delivery of Health Care*, 35 SAN DIEGO L. REV. 135 (1998) (focusing on Title VI); Sara Rosenbaum et al., *Civil Rights in a Changing Health Care System*, 16 HEALTH AFFAIRS 90 (1997); Sidney D. Watson, *Reinvigorating Title VI: Defending Health Care Discrimination—It Shouldn't Be So Easy*, 58 FORDHAM L. REV. 939 (1990); Kenneth R. Wing, *The Community Service Obligation of Hill-Burton Health Facilities*, 23 B.C. L. REV. 577 (1982); *see generally* GEORGE ANNAS ET AL., AMERICAN HEALTH LAW (1990).

transformed the delivery of health care services.[6] Yet the racial and ethnic disparities in health status and health care access that gave rise to the assembly still remain.

As a post-conference report to the Henry J. Kaiser Family Foundation (LDF Report) indicates, generations of African Americans, particularly the poor, have been exposed to greater health risks than Whites and have been more likely to contract preventable illness, to suffer from chronic and often disabling conditions, and to die prematurely.[7] Indeed, disparities in both exposure to health hazards and access to health care continue to threaten not only quality of life, but the very possibility of longevity. Consider the following:

1. African American infants are twice as likely as Caucasian infants to die before reaching their first birthday.[8]

2. African American women have a life expectancy five years shorter than Caucasian women.[9]

3. The life expectancy for African American men is seven years shorter

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[6] As Marsha Gold noted in the opening pages of a recent volume on the emerging issues related to managed care, managed care has already reshaped the private insurance market and is now having a deep impact on the way in which both the Medicaid and Medicare programs operate. MARSHA R. GOLD, *The Evolution of Managed Care*, *in* CONTEMPORARY MANAGED CARE: READINGS IN STRUCTURE, OPERATIONS, AND PUBLIC POLICY 5 (Gold ed., 1998). Not only has managed care "become the dominant form of coverage for privately insured individuals," but substantial and growing proportions of Medicaid and Medicare beneficiaries have now also joined the ranks of managed care enrollees. *Id.*

[7] *See* LDF Report, *supra* note 5, at 1-2. This article focuses specifically on the need to address inequities in the financing and delivery of health care as they affect poor African American communities, since this has been the core of the author's work. Nonetheless, such inequities also fall with great weight on other communities of color. *See, e.g., Hispanic-American Health CBM 94-6* (Karen Patrias ed.) (1994), *at* http://www.nlm.nih.gov/pubs/cbm/hispanic.html (last visited July 8, 1998); *see generally* HEALTH RESOURCES AND SERVICES ADMIN., U.S. DEPT. OF HEALTH AND HUMAN SERVICES, HEALTH STATUS OF MINORITIES AND LOW-INCOME GROUPS (3rd ed. 1992).

Specific morbidity and mortality rates differ among racial and ethnic groups, however, making separate analysis most appropriate for some purposes. *See generally* Herbert W. Nickens, *The Role of Race/Ethnicity and Social Class in Minority Health Status*, 30 H.S.R. 151 (1995). The use of the categories "White" and "non-White," for example, can obscure the unique experience and health status of each population. *See* HEALTH RESOURCES AND SERVICES ADMIN., U.S. DEPT. OF HEALTH AND HUMAN SERVICES, HEALTH STATUS OF MINORITIES AND LOW-INCOME GROUPS 15-16 (3rd ed. 1992) (comparing mortality rates by cause for Whites, Blacks, American Indians and Alaskan Natives, and Asians). Indeed, tremendous variation can exist even within particular categories of ethnicity. *See* Jose E. Beccera et al., *Infant Mortality Among Hispanics*, 265 JAMA 217 (1991) (finding neonatal mortality risks significantly higher for Puerto Rican Islanders and continental Puerto Ricans than for Cuban-Americans and Mexican-Americans).

[8] Blacks experienced an infant mortality rate of 14.2, as compared to 6.0 for Whites. Bureau of the Census, *Statistical Abstract of the United States: 1998* (Table 134: "Infant, Maternal, and Neonatal Mortality Rates and Fetal Mortality Ratios, by Race: 1980 to 1996") (1996 data).

[9] For black females, life expectancy at birth is 74.2 years, as compared to 79.6 for white females. Bureau of the Census, *Statistical Abstract of the United States: 1998* (Table 128: "Expectation of Life at Birth, 1970 to 1996, and Projections, 1995 to 2010") (1996 data).

than for Caucasian men.[10]

Indeed, as the *New York Times* reported in 1998, "[W]hen it comes to health, studies show a stubborn, daunting, and in some respects, growing disparity between Black and White Americans."[11] In particular, despite the economic gains of the 1990s, African Americans continue to receive less and lower quality health care than Whites.[12]

A. Discrimination in the Delivery of Care

There is no organized civil rights bar to attack discrimination in the provision of health care. Moreover, unlike in the employment[13] and housing[14] contexts, there is no independent federal statutory framework governing civil rights enforcement in health care access, aside from Title VI of the Civil Rights Act of 1964. However, racial disparities in access to health care are attributable to historic patterns of exclusion, mistreatment and discrimination.[15] As historian Rosemary Stevens writes, throughout the twentieth century "[H]ospitals, as social institutions, carried (and enhanced) prevailing assumptions about social class and racial divisions in the United States . . . ."[16] Stevens also noted that historically African Americans in need of medical care were denied services entirely, were placed in segregated wards providing inferior care in the least desirable facilities, or were forced to seek out alternative forms of treatment.[17] Until

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[10] For black males, life expectancy at birth is 66.1 years, as compared to 73.8 for white males. *Id.*

[11] Peter T. Kilbom, *Health Gap Grows, With Black Americans Trailing Whites, Studies Say*, N.Y. TIMES, Jan. 26, 1998, at A16.

[12] *Id.*

[13] 42 U.S.C. § 2000e *et seq.* ("Title VII").

[14] 42 U.S.C. § 3601 *et seq.* ("Title VIII") (Fair Housing Act).

[15] *See generally* DAVID BARTON SMITH, HEALTH CARE DIVIDED: RACE AND HEALING A NATION (1999) [hereinafter SMITH, HEALTH CARE DIVIDED]; Vemellia R. Randall, *Reforming an Unjust Health System to Meet the Needs of African-Americans*, 3 Health Matrix 127, 146-48 (1993); David B. Smith, *Addressing Racial Inequalities in Health Care: Civil Rights Monitoring and Report Cards*, 23 J. OF HEALTH POLITICS, POL. AND LAW 75, 79-93 (1998).

[16] ROSEMARY STEVENS, IN SICKNESS AND IN WEALTH: AMERICAN HOSPITALS IN THE TWENTIETH CENTURY 50 (1989); *see also* David B. Smith, *Population Ecology and the Racial Integration of Hospitals and Nursing Homes in the United States*, 68 MILBANK QUART. 561 (1990) (historical account of segregation within and efforts to integrate health care institutions); WILLIAM M. COBB, MEDICAL CARE AND THE PLIGHT OF THE NEGRO 201, 208-20 (1947).

[17] STEVENS, *supra* note 16, at 50. Stevens describes, for example, the availability of hospital care in the 1920s:

> Pay beds for black Americans were largely nonexistent, and where they existed, in all-black hospitals, services were often poor and sometimes dangerous. Almost a quarter of all general hospitals in the United States in 1922 reported that they limited their services to 'whites'. . . .

1963, federal policy sanctioned segregation in federally assisted and federally administered facilities.[18]

There can be no doubt that the disparity in health status previously mentioned reflects, in no small part, the widespread continuation of discriminatory and segregatory practices in the provision of medical services.[19] Indeed, recent studies have made clear that economic factors such as income and insurance status are important, but cannot fully explain racial disparities in the delivery of health care services.[20] For example, research on health care utilization by the population insured through the Medicare program indicates that older black men on Medicare receive heart bypass surgery about one-fourth as often as similarly situated Whites.[21] In the rural Southeast, white Medicare patients are seven times more likely to have the surgery as Blacks.[22] Referencing his study on major coronary procedures in veterans hospitals, Dr. John Ayanian noted, "[T]hat race can affect medical care in ways that are not simply related to socioeconomic status, because racial differences occurred in a system where care is free and black and white patients are more similar in socioeconomic status than the general population."[23] Other research found that V.A. Medical Centers provided African American veterans with acute myocardial infarction with "substantially fewer cardiac procedures than whites."[24] In the mid-1990s,

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Id. at 137. *See also* COBB, *supra* note 16, at 208-20.

[18] For a discussion of inequality by race and class in Veterans Administration hospitals, see STEVENS, *supra* note 16, at 222, 386 n.49. Segregation in, and discrimination by, Hill-Burton facilities are also discussed. *Id.* at 219, 252-54 (Hill-Burton "allowed for 'equitable provision' to be made through separate but equal hospital facilities."). However, the "separate but equal" provision of the Hill-Burton Act was held unconstitutional in *Simkins v. Moses H. Cone Memorial Hosp.*, 323 F.2d 959 (4th Cir. 1963), *cert. denied*, 376 U.S. 938 (1964).

[19] *See* Marsha Lillie-Blanton et al., *Racial Differences in Health: Not Just Black and White, but Shades of Gray*, 17 ANN. REV. PUBLIC HEALTH 411 (1996) (studies attempting to disentangle the effects of race or ethnicity and social class on health status provide evidence that socioeconomic conditions are a major factor but not sufficient to explain racial differences in a number of outcomes, such as infant mortality and the incidence of hypertension).

[20] *See* Mita K. Giacomini, *Gender and Ethnic Differences in Hospital-Based Procedure Utilization in California*, 156 ARCHIVES OF INTERNAL MEDICINE 1217 (1996); Beth Hahn, *Children's Health: Racial and Ethnic Differences in the Use of Prescription Medications*, 95 PEDIATRICS 727 (1995); Council on Ethical & Judicial Affairs of the AMA, *Black-White Disparities in Health Care*, 263 JAMA at 2344, (1990); Funkhouser & Moser, *Is Health Care Racist?*, 12 ADV. NURS. SCI. 47 (1990).

[21] *Fewer Heart Bypasses for Blacks on Medicare*, N.Y. TIMES, Mar. 18, 1992, at B6. *See also* Marian E. Gornick et al., *Effects of Race and Income on Mortality and Use of Services Among Medicare Beneficiaries*, 335 NEW ENGL. J. MED. 791, 794 (1996) (adjusting rates of use of services among black and white Medicare patients for differences in income affected disparities in use relatively little); Katherine L. Kahn et al., *Health Care for Black and Poor Hospitalized Medicare Patients*, 271 JAMA 1169 (1994) (finding quality of hospital care for similarly insured Medicare patients "influenced" by the patient's race, among other factors); J.J. Escarce et al., *Racial Differences in the Elderly's Use of Medical Procedures and Diagnostic Tests*, 83 AM. J. PUBLIC HEALTH 948 (1993) (pervasive racial differences in the use of services by the elderly cannot be explained by the differences in the prevalence of specific clinical conditions or financial barriers).

[22] *Id.*

[23] John Z. Ayanian, *Race, Class, and the Quality of Medicine*, 271 JAMA 1207, 1208 (1994).

[24] Eric D. Peterson, *Racial Variation in Cardiac Procedure Use and Survival Following Acute Myocardial Infarction in the Department of Veterans Affairs*, 271 JAMA 1175 (1994). *See also* Jeff

the American Medical Association (AMA) formally acknowledged the continuation of racially-based disparities in care. The Report of the AMA Board of Trustees noted that despite the many advances in medicine and health care during the past quarter of a century, "racial problems are chronic."[25]

These "racial problems" come in many guises. As Jane Perkins, of the National Health Law Program, wrote, "The most obvious difference between majority and minority health care is that people of color are generally served by a delivery system separate from that serving whites."[26] Physicians, who have historically maintained the discretion to admit patients into their practice, may choose not to treat individuals based on their race or ethnicity or to cap the number of African Americans or low-income people of color without repercussion. Medical professionals may also feel some pressure to limit the number of African Americans and Latinos in their practice because hospitals may deny staff privileges to physicians who are perceived as bringing a different, and allegedly less desirable, group of patients into the facility.[27] In a similar vein, a recent study reported in the *Journal of the American Medical Association* investigated the problems physicians may be encountering with managed care organizations (MCOs).[28] The study found that the physicians in managed care "had significantly lower percentages of uninsured and non-white patients in their practices."[29] These findings suggest that physicians with a greater number of uninsured or non-white patients may be less likely to be offered opportunities to participate in managed care networks.[30]

Whittle et al., *Racial Differences in the Use of Invasive Cardiovascular Procedures in the Department of Veterans Affairs Medical System*, 329 NEW. ENG. J. MED. 621 (1993) (concluding that Whites eligible to receive care in V.A. hospitals are more likely than their black counterparts to undergo invasive cardiac procedures even when analysis adjusts for financial and other factors); Mark B. Wanneker & Arnold M. Epstein, *Racial Inequalities in the Use of Procedures for Patients with Ischemic Heart Disease in Massachusetts*, 261 JAMA 253 (1989) (finding substantial interracial differences in cardiac procedures rates in Massachusetts hospitals).

[25] AMA, "Report on Racial and Ethnic Disparities in Health Care" (Board of Trustees Report 50-I-95), at 2.

[26] Jane Perkins, *Race Discrimination in America's Health Care System*, 27 CLEARINGHOUSE REV. 371, 375 (1993).

[27] *See* United States Commission on Civil Rights, "The Health Care Challenge: Acknowledging Disparity, Confronting Discrimination, and Ensuring Equality," at 108 (1999) (discussing the need for additional attention to address discrimination against minority physicians and the link between the representation of minorities on medical staffs and access to quality care for people of color). *See, e.g.*, Chavis v. Women's Hospital of the Memorial Medical Center for Long Beach, Los Angeles County Superior Court No. C711144.

[28] Andrew B. Bindman et al., *Selection and Exclusion of Primary Care Physicians by Managed Care Organizations*, 279 JAMA 675 (1998).

[29] *Id.*

[30] *Id.* at 679. The authors' comment:

> Selective contracting for managed care may be occurring at the expense of physicians who provide a greater share of charity care. Rather than rewarding these physicians for their socially responsible deeds, the health care marketplace seems to be excluding them.

Indeed African American medical professionals, who on average care for a significantly higher number of black patients than their white counterparts,[31] report racial discrimination in all aspects of the practice of medicine, including peer review, obtaining staff privileges, hospital staff promotions, malpractice suits, private insurance oversight, and the referral practices of white colleagues.[32]

As health care consumers, African Americans must navigate financing and delivery systems in which the obstacles to care are many and discrimination is pervasive.[33] For many African Americans and other minorities, racial and ethnic barriers are compounded by economic disadvantage. African Americans and Latinos are more likely to be uninsured than Whites, and significantly less likely to be covered by private, employment-related insurance.[34] However, independent of insurance, non-white children still have less access to care than their white counterparts.[35] Similarly, poor women of color are particularly burdened by restrictions on reproductive health services because of the limited availability of services, the likelihood of scheduling difficulties at overcrowded facilities, and greater barriers of distance and mobility.[36]

African Americans are also at a disadvantage in the competition to receive organ transplants.[37] While working as a staff attorney at LDF, the

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Id.

[31] Miriam Komaromy et al., *The Role of Black and Hispanic Physicians in Providing Health Care for Underserved Populations*, 334 NEW ENG. J. MED. 1305, 1305 (1996) (finding that black physicians care for significantly more black and Medicaid patients and Hispanic physicians care for significantly more Hispanic and uninsured patients than white physicians).

[32] M. Byrd et al., *African-American Physicians' Views on Health Reform: Results of a Survey*, 86 J.N.M.A. 191, 191 (1994).

[33] *See* LAURIE KAYE ABRAHAM, MAMA MIGHT BE BETTER OFF DEAD: THE FAILURE OF HEALTH CARE IN URBAN AMERICA (1993); *The Health Divide*, NEWSDAY (1998) (eight day series of reports on racial disparities in the distribution of health care in the New York metropolitan area, focusing, in particular, on cardiac care, organ transplants, infant mortality, diabetes, distrust and alienation, medical myths, and centenarians) http://www.newsday.com/features/health/hrseries.htm (last visited Dec. 9, 1998).

Although not the primary focus of the discussion herein, cultural and linguistic differences can pose formidable barriers to access for members of particular racial and ethnic groups. *See* Pancho H. Chang & Julia Puebla Fortier, *Language Barriers to Health Care: An Overview*, 9 J. OF HEALTH CARE FOR THE POOR AND UNDERSERVED S5 (1998) (supplemental issue devoted to topic) and Marcasa R. Isaacs & Marva P. Benjamin, *Towards a Culturally Competent System of Care*, Volume II (1991).

[34] *See* The Commonwealth Fund, "National Comparative Survey of Minority Health," (New York, Mar. 20, 1995), at 1.

[35] *See* David L. Wood et al., *Access to Medical Care for Children and Adolescents in the United States*, 86 PEDIATRICS 666 (1990) (finding also that non-white, poor, or uninsured children are less likely to have a regular source of care; more likely to use emergency rooms, community clinics, and hospital outpatient departments as their regular providers; and more likely to encounter financial barriers to health care).

[36] Brief of *Amici Curiae* of the NAACP Legal Defense and Educational Fund, Inc., and Other Organizations, *Planned Parenthood of Southeastern Pennsylvania v. Casey*, 505 U.S. 833 (1992) (Nos. 91-744 and 91-902).

[37] *See* Robert S. Gaston, *Racial Equity in Renal Transplantation: The Disparate Impact of HLA-Based Allocation*, 270 JAMA 1352 (1993). *See also* Robert Fresco, *Long, Frustrating Delay for a*

author of this article received calls from families seeking representation in their effort to pressure the National Bone Marrow Transplant network to increase outreach to minority communities, an effort that might make real the statutory promise that minorities will have a comparable opportunity for bone marrow transplants.[38] Approximately 75% of white patients in need of a bone marrow transplant are able to find a donor whose antigens match appropriately through the National Bone Marrow Donor Program (NMDP). By contrast, fewer than 20% of African American patients can find a donor through the program. The gap is due, in part, to the underrepresentation of African Americans in the NMDP's donor pool, the composition of which is largely a function of outreach efforts.[39]

Complaints were also received by the author that ambulance corps and physicians still engage in practices such as racial "steering" (sending different categories of patients to different locations for care), and "cherry picking" (selecting certain patients for referral to premier facilities). And providers continue to "dump" unwanted patients by refusing treatment or transferring patients elsewhere.[40] Two recent studies have found that "the

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Kidney: Blacks Wait for Transplant Twice as Long as Whites Do, NEWSDAY (1998) (in "Health Divide" series); Barbara A. Noah, *Racist Health Care?*, 48 FLA. L. REV. 357, 362-66 (1996); Benjamin Mintz, *Analyzing the OPTN Under the State Action Doctrine—Can UNOS's Organ Allocation Criteria Survive Strict Scrutiny?*, 28 COLUM. J.L. & SOC. PROBS. 339 (1995) (applying equal protection analysis to the criteria used for the allocation of kidneys); ABRAHAM, *supra* note 33, at 179-97; Clive Callendar et al., *Organ Donation and Blacks: A Critical Frontier*, 325 NEW ENGL. J. MED. 442 (1991); Bertram L. Kasiske et al., *The Effect of Race on Access and Outcome in Transplantation*, 324 NEW ENGL. J. MED. 302 (1991); Held et al., *Access to Kidney Transplantation: Has the United States Eliminated Income and Racial Differences?*, 148 ARCHIVES OF INTERNAL MED. 2594 (1988).

[38] 42 U.S.C. 274k(b)(3) (section of statute establishing National Bone Marrow Donor Registry requiring the registry to increase the representation of individuals from racial and ethnic minority groups in the donor pool, "in order to enable an individual in a minority group, to the extent practicable, to have a *comparable chance* of finding a suitable donor as would an individual not in a minority group") (emphasis added).

[39] *See* Katie McCabe, *Window of Hope*, READER'S DIGEST 79 (July, 1992) (chronicling one African American family's efforts to find a donor). Since 1989, however, in response to pressure and a campaign initiated by the family of JoAnne Johnson, an African American teenager who was unable to find a match before succumbing to leukemia, the National Bone Marrow Donor Registry has increased its efforts to reach out to underrepresented groups. "Reauthorization of the National Bone Marrow Registry: Hearing before the Committee on Labor and Human Resources," 101st Cong., 2nd Sess. 21, 123 (1990); GAO, "Bone Marrow Transplants: National Program Has Greatly Increased Pool of Potential Donors" (Nov. 1992) (GAO/HRD-93-1), at 6-7; *see also* HHS Office of Minority Health, "Closing the Gap" (May 1998) (relating to organ donation and transplant within minority communities).

[40] *See* Robert L. Schiff et al., *Transfers to a Public Hospital: A Prospective Study of 467 Patients*, 314 NEW ENG. J. MED. 552 (1986). Medical facilities also use other patient referral and admission practices that limit access for patients of color, including (a) the exclusion of physicians on staff who serve higher proportions of African Americans and/or accept Medicaid and other lower income patients, (b) the requirement that patients pay pre-admission deposits as a condition of obtaining care, and (c) the admission of only patients of physicians with staff privileges when the patient population is itself exclusive and does not reflect the racial composition of the local community. Vernellia R. Randall, *Racist Health Care: Reforming an Unjust Health System to Meet the Needs of African Americans*, 3 HEALTH MATRIX 127, 149 (1993) and Stan Dorn et al., *Anti-Discrimination Provisions and Health Care Access: New Slants on Old Approaches*, CLEARINGHOUSE REV. 439, 441 (1986). *See also* Casandra Q. Butts, "The Color of Money: Barriers of Access to Private Health Care

need for long-term care is higher among Blacks and Latinos than Whites, but their use of some long-term care services is substantially lower."[41] The under-representation of African Americans in nursing homes is demonstrably related to discrimination on the bases of race, socioeconomic status, and insurance, or a combination thereof.[42]

Perhaps most troubling is that, as a result of a myriad of decisions made by individuals and organizations over decades, many African American communities are simply underserved, left out of the mainstream of medicine and unable to take advantage of pharmaceutical and technological advances. Alan Sagar, Assistant Professor at Brandeis University, identified this fundamental problem—the dismantling and lack of medical infrastructure—as far back as 1980. In his testimony before Congress about urban hospital closures and relocations, Sagar reported that minority neighborhoods are likely to be associated with the absence or departure of physicians in private practice, which, in turn, undermines the viability of public inner-city facilities.[43] In addition, the conversion of

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Facilities for African Americans," (LDF Draft Conference Paper, 1991).

[41] Mary L. Grady, *Use of Long-Term Care Varies According to Race*, 215 *Research Activities* (May 1998), *available at* http://www.ahrq.gov/research/may98/ra3.htm (reporting on S. P. Wallace et al., *The Persistence of Race and Ethnicity in the Use of Long-Term Care*, 53 J. OF GERONTOLOGY: SOCIAL SCIENCES, S104, and S. P. Wallace et al., *The Impact by Race of Changing Long-Term Care Policy*, 9 J. OF AGING AND SOC. POLICY 1). Research has also documented differential diagnosis and treatment of mental health patients on the basis of race and ethnicity. For example, African Americans are overdiagnosed with schizophrenia (versus depression) and overrepresented at state inpatient facilities. *See* William B. Lawson, *Clinical Issues in the Pharmacotherapy of African-Americans*, 32 PSYCHOPHARMACOL. BULL. 275 (1996); William B. Lawson et al., *Race as a Factor in Inpatient and Outpatient Admissions and Diagnosis*, 45 HOSP. & COMMUNITY PSYCH. 72 (1994); Lonnie R. Snowden & Freda K. Cheung, *Use of Inpatient Mental Health Services by Members of Ethnic Minority Groups*, 45 AM. PSYCHOL. 347 (1990); *see also* Wilder v. Chater, 64 F.3d 335, 337 (7th Cir. 1995) (opinion by Judge Posner discussing the likelihood of misdiagnosis of mental illness such as depression in African American communities). The overdiagnosis of African Americans as schizophrenics, rather than as suffering from depression or other disorders, has also been discussed with regard to the determination of patient competency to make treatment decisions. *See* Susan Stefan, *Race, Competence Testing, and Disability Law: A Review of the MacArthur Competence Research*, 2 PSYCHOL. PUB. POL'Y. AND L. 31, 33-34 (1996).

[42] David B. Smith, *Population Ecology and the Racial Integration of Hospitals and Nursing Homes in the United States*, 68 MILBANK QUART. 561, 580-90 (1990). *See also* David B. Smith, *The Racial Segregation of Hospital Care Revisited: Medicare Discharge Patterns and Their Implications*, 88 AM. J. PUB. HEALTH 461 (1998); David B. Smith, *The Racial Integration of Health Facilities*, 18 J. HEALTH POL. POL'Y & L. 851 (1993); Marcel E. Salive et al., *Predictors of Nursing Home Admission in a Biracial Population*, 83 AM. J. PUB. HEALTH 1765 (1993) (demonstrating racial differences in nursing home use not explained by financial or social support or physical or cognitive impairment); Linton v. Comm'r of Health and Env't, 779 F. Supp. 925 (M.D. Tenn., 1990) (finding Tennessee's bed certification policy in violation of both the Medicaid Act and Title VI of the Civil Rights Act of 1964); Taylor v. White, 132 F.R.D. 636 (E.D. Penn. 1990); "New York State Nursing Home Task Force Final Report," (June, 1986) (report of task force comprised of members from the state Division of Human Rights, Department of Health, and Department of Law, among others); Hickman v. Fowinkle, No. C-80-2014-M (W.D. Tenn., filed Jan. 30, 1980) (see complaint and consent judgment).

[43] Sagar, Problems Facing Financially Troubled Hospitals: Field Hearings Before the Subcomm. On Health of the Comm. on Ways & Means, House of Representatives, 96th Cong. 191 (1980) (testimony of Alan Sagar, Assistant Professor Brandeis University); *see also* Terry v. Methodist Hop. of Gary, Nos. H-76-373 & H-77-154 (N.D. Ind.) (consent decree entered into on June 8, 1979).

public and non-profit facilities to for-profit status has also diminished the accessibility of care by poor communities.[44] As noted in a recent study, the result of this process is that "[c]ommunities with high proportions of Black and Hispanic residents [are] four times as likely as others to have a shortage of physicians, regardless of community income."[45]

B. The Profound Consequences of Failing to Provide Adequate Health Services to Low Income African Americans

Statistics reflecting disparities in health care access fail to capture the profound alienation that many African Americans feel from the predominantly white health care industry as a result of generations of mistreatment, exclusion and virtually unchecked discrimination along the color line. Recent revelations that researchers were performing experiments with psychiatric drugs on African American and Latino boys were of little surprise to those in medically underserved areas who have no basis for trust in the medical profession or health care industry.[46] As Laurie Kaye Abraham wrote in her book on the barriers to access faced by a low-income African American family in Chicago, "A fair number of Blacks are convinced, not without reason, that doctors do not always have their best interests at heart. To a degree that confounds many Whites, they worry that they could become unwitting subjects in dangerous human experiments."[47]

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[44] *See, e.g.*, Jones & Clifford, *The Privatization of Treatment Services for Alcohol Abusers: Effect on the Black Community*, 82 J. NAT'L MED. ASS'N 337 (1990).

[45] Komaromy et al., *The Role of Black and Hispanic Physicians in Providing Health Care for Underserved Populations*, 334 NEW ENG. J. MED. 1305, 1305 (1996).

[46] According to reports published in the *New York Times*, in the mid-1990s researchers at the New York State Psychiatric Institute gave approximately one hundred boys, many of whom were Black or Latino, intravenous doses of fenfluramine "to test a theory that violent or criminal behavior may be predicted by levels of certain brain chemicals." Patient advocacy groups who exposed the experiments charged that the now-banned fenfluramine was administered though it carried substantial health risks and promised no hope of medical benefit. Philip J. Hilts, *Experiments on Children Are Reviewed*, N.Y. TIMES, Apr. 15, 1998, at B3.

[47] ABRAHAM, *supra* note 33, at 203. According to reports published by local newspapers, distrust was evident, for example, at a December 1998 AIDS forum held in Harlem. Belief in conspiracy theories and skepticism that HIV is the cause of AIDS were "vividly demonstrated" at the Forum:

> Throughout the afternoon, to thunderous applause and heartfelt approbation, speakers presented a score of assaults on AIDS orthodoxy. Of the dozen or so speakers, only one subscribed to the theory that H.I.V. was what was making people sick—and he argued that it was being transmitted intentionally to blacks through World Health Organization vaccine programs, part of what he described as a genocidal project.

David France, *Challenging the Conventional Stance on AIDS*, N. Y. TIMES, Dec. 22, 1998, at F6, col. 2. In its coverage, the *Village Voice* profiled Brother Phillip Valentine, a nature healer, whom the author quoted as saying, "The only myths about AIDS circulating in the black community are those purposely put there by the propaganda machinery of the Centers for Disease Control and the pharmaceutical companies." Peter Noel, *We're Saving Our Own Lives*, THE VILLAGE VOICE, at 51

Indeed, there is an extensive record of medical experimentation on African Americans, from the Tuskegee Syphilis Study[48] to the use of prisoners for pharmaceutical testing.[49] The record includes an investigation of whether Dilantin would increase oxygen flow to children delivered by cesarean section, which was conducted by an anesthesiologist who never obtained consent from the 240 pregnant women who participated in the study.[50]

Medical experimentation may be the most flagrant cause of alienation, but pervasive mistreatment combined with systemic discrimination over generations have reinforced a deep distrust. Stories of segregation and abuse at the hands of white medical professionals are now woven into the fabric of African American lore. Two generations ago, anthropologist and author Zora Neale Hurston wrote of her experience with a white specialist in Brooklyn, New York. Hurston's appointment had been made over the telephone, and the receptionist was "obviously embarrassed" when she arrived. Hurston was ultimately taken to and examined in a closet with soiled towels and uniforms rather than the examination room.[51] In like manner, Maya Angelou has recounted her ordeals at the hands of white physicians in the South. Angelou describes being taken by her Grandmother across the railroad tracks to a white dentist. Ignoring her pain entirely, the dentist refused to treat Angelou's toothache, saying "my policy is I don't treat colored people." When Angelou's grandmother pleaded with him, he replied, "My policy is I'd rather stick my hand in a dog's mouth than in a nigger's."[52]

Deep suspicion continues today, exacerbated by individual incidents of mistreatment as well as structural inequalities. At a meeting the author attended at a public housing complex in New York in the 1990s, for example, tenants discussed the poor treatment they had received at area hospitals. Residents spoke of racial and economic segregation at not-for-profit hospitals. Privately insured patients, a disproportionate number of whom were White, were placed in one wing of the hospital, while uninsured patients and Medicaid recipients were placed in another. This occurred despite the fact that New York State's Medicaid program fully funded the hospital for inpatient care.[53] Indeed, subsequent investigations

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(Dec. 22, 1998). Valentine is among those who, after the death of Kwame Ture (formerly known as Stokely Carmichael), blamed western medicine, and chemotherapy in particular, for poisoning and killing the well known leader. *Id.*

[48] James Jones, BAD BLOOD: THE TUSKEGEE SYPHILIS EXPERIMENT—A TRAGEDY OF RACE AND MEDICINE (1981).

[49] Allen M. Hornblum, ACRES OF SKIN: HUMAN EXPERIMENTS AT HOLMESBURG PRISON: A TRUE STORY OF ABUSE AND EXPLOITATION IN THE NAME OF MEDICAL SCIENCE (1998).

[50] ABRAHAM, *supra* note 33, at 203-09.

[51] Zora Neale Hurston, *My Most Humiliating Jim Crow Experience*, *in* TRIALS, TRIBULATIONS, AND CELEBRATIONS: AFRICAN-AMERICAN PERSPECTIVES ON HEALTH, ILLNESS, AGING AND LOSS 23, 23-24 (Marian G. Secundy ed., 1992).

[52] MAYA ANGELOU, I KNOW WHY THE CAGED BIRD SINGS 157-60 (1993).

[53] *See* ELI GINZBERG ET AL., *Improving Health Care of the Poor: The New York City Experience*

at New York's Mt. Sinai Hospital revealed similar patterns,[54] as well as the assignment of privately insured African Americans to the ward usually reserved for the poor.[55] In a series of articles that made public the discriminatory practices at Mt. Sinai, Annette Fuentes reported that the wards were not only separate, but also unequal.[56] Karen Gagnon, a privately insured African American patient who had toured the private floor but was assigned to a room on the ward usually reserved for the poor, compared the two: "You'd think it was a different hospital."[57] Fuentes also quoted a nurse at Mt. Sinai who acknowledged the disparities in services: "They [the patients on the predominantly minority ward] don't get the same education and treatment, like information on infant care and breast feeding. . . ."[58] Indeed, the public housing tenants agreed that what they called the "private" and "public" wings contrasted sharply, that they were "different worlds."[59] In the public ward, they had seen feces in open areas, their beds were not changed as often or often enough, and they failed to receive adequate and timely attention from the nursing staff.[60]

Although public hospitals serve a disproportionate number of poor people of color in the United States, New York public housing tenants at the aforementioned meeting also expressed suspicion of services available at area public hospitals. More than one recounted how he or she had heard of someone who had been "displaced" there for a few days.[61] A number explained that they refused to go to the public hospital because "they kill people there."[62] Although overcrowded clinics and busy emergency rooms attest to the fact that many individuals nonetheless present themselves at

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56 (1977). Indeed, in defense of its practice of segregating obstetric patients by method of payment, New York's Mt. Sinai Hospital argued that the problem stemmed from inadequacy of Medicaid payments to private physicians, not any disparity in hospital inpatient reimbursement rates. As a result of low payment rates, relatively few private physicians provide services to Medicaid recipients, and the hospital staffs become the provider of inpatient care. Placing Medicaid recipients on uninsured patients apart from the insured, then, served the goal of "clinical efficiency." *Equality of Treatment in Providing Health Care Services: Hearing before New York Assembly Subcommittee on Urban Health Care*, May 9, 1994 (N.Y. 1999) at 4 (Testimony of Barry Freedman, Director of the Mount Sinai Hospital).

[54] *Id.*

[55] Fuentes, *Biased Care: Hospital Segregation Under State Review*, N.Y. DAILY NEWS, Oct. 18, 1993; In the Matter of U.S. HHS and the Mount Sinai Hospital, No. 02-94-7801 (Resolution Agreement, Mar. 1, 1994). *See also* Sack, *Inquiry Finds Hospital Had 2 Categories*, N. Y. TIMES, Apr. 29, 1994, at 25 (describing how New York City's Columbia Presbyterian Medical Center was also found to run two separate maternity wards—one for the privately insured and one for those who were either uninsured or insured through Medicaid, and stating that investigations of two additional hospitals were underway).

[56] Fuentes, *supra* note 55.

[57] Fuentes, *supra* note 55.

[58] *Id.*

[59] Engelman 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*, 60 BROOK. L. REV. 239, 247 (1994).

[60] *Id.*

[61] *Id.*

[62] *Id.*

public hospitals, the high level of alienation associated with these comments merits attention. Such distrust has ramifications for the timeliness of care seeking, the success of public information campaigns and preventative medicine, and compliance with prescribed courses of treatment.[63]

C. Litigation to Complement Other Areas of a Civil Rights Agenda

Although the way in which access to health care specifically intersects with other issues is beyond the scope of this paper, it is worth noting how expertise on health issues and an active health docket complement other areas of a civil rights agenda.

Since the publication of a 1987 study showing that race, even more than socioeconomic status, correlates with the location of hazardous waste facilities,[64] communities across the country have mobilized around issues of environmental justice. The environmental justice movement has grown in response to concerns that poor people of color are disproportionately exposed to health hazards and that both the placement of such hazards and the failure to clean up toxic sites in low-income communities of color follow predictable patterns, representing various forms of "environmental racism."[65] Litigation and advocacy aiming to achieve equity in the provision of health services complements an environmental justice docket. Indeed, to some degree they overlap. Consider, for example, litigation to challenge the failure of states to require lead blood tests in compliance with federal requirements that all children on Medicaid receive early and periodic screening, diagnosis and treatment (EPSDT).[66] Even where the health and environmental dockets diverge, lawyers and other staff may find themselves comparing notes on legal strategies (for example, whether to rely on rights under Title VI of the Civil Rights Act of 1964, 42 U.S.C. 2000d, and its implementing regulations or whether to pursue other procedural and substantive claims under state and federal law); sharing factual data; sharing information on experts (for example, regarding

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[63] *See, e.g.*, Thomas and Crouse Quinn, *The Tuskegee Syphilis Study, 1932-1972: Implications for HIV Education and AIDS Risk Education Programs in the Black Community*, 81 AMER. J. PUB. HEALTH 1499 (1991); *see also* Vernellia R. Randall, *Does Clinton's Health Care Reform Proposal Ensure (E)qual(ity) of Health Care for Ethnic Americans and the Poor?*, 60 BROOK. LAW REV. 167, 206-09 (1994) (noting that distrust and miscommunication are barriers to access).

[64] *See* Commission for Racial Justice, "Toxic Wastes and Race in the United States: A National Report on the Racial and Socio-Economic Characteristics of Communities with Hazardous Waste Sites," at 15 (1987).

[65] Bullard & Wright, *The Quest for Racial Environmental Equity: Mobilizing the African American Community for Social Change*, 3 SOC'Y AND NATURAL RESOURCES 301, 302 (1990).

[66] *See Matthews v. Coye*, No. C-90-3620 EFL (N.D.Cal. Oct. 1991) (settlement). 42 U.S.C. § 1396d(r).

community level demographics and the incidence of chronic conditions such as childhood asthma); and discussing approaches to working with the many community groups seeking representation.

Potential also exists for productive linkage with the area of criminal justice. Conceptually, the deprivation of health care can be seen as one of the conditions, along with the failure to provide educational opportunities and decent, safe housing, that leads along a continuum to the criminalization of many low-income African American children.[67] Moreover, any inquiry by the health docket into discriminatory referral and treatment patterns in mental health, an area ripe for investigation, could benefit from the information and expertise acquired during years of capital punishment litigation.[68] Finally, given both the proportion of young African American men involved in the criminal justice system and the tragic dimensions of the HIV/AIDS epidemic within that population, activists in those two areas could consider the possibility of a joint exploration into issues such as prison health.[69]

Finally, problems of access to health care also intersect with the availability of employment opportunities as well as job conditions. Most

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[67] For discussion of the criminalization process generally, and the relationship between the conditions of poverty and subsequent criminal activity, see Richard Burr & Mandy Welch, *Killing Kids Who Kill: Desecrating the Sanctuary of Childhood*, 29 St. Mary's L. J. 929, 944 (1998) (noting statistics on the correlation of youth poverty and crime); "Carter Center Symposium on the Death Penalty," 14 *Ga. St. U.L. Rev.* 329, 347, 352-54 (remarks of William McFeely and Bryan Stevenson); Jerome G. Miller, Search and Destroy: African-American Males in the Criminal Justice System (1996); Jerome G. Miller, *From Social Safety Net to Dragnet: African American Males in the Criminal Justice System*, 51 Wash. & Lee L. Rev. 479 (1994) (reviewing and drawing conclusions from analyses of non-white male involvement in the criminal justice system). *See also Report of the National Advisory Commission on Civil Disorders* (New York: E.P. Dutton & Co., 1968), at 269-73 (citing disparities in health status and health access are among the conditions causing destruction of urban environments and social disorder); Craig J. Forsyth, *Sociology and Capital Murder: A Question of Life or Death, in* Witnessing for Sociology: Sociologists in Court 57-69 (Pamela J. Jenkins & Steve Kroll-Smith eds., 1996) (sociological interpretations of criminal behavior); Alex Kotlowitz, There Are No Children Here: The Story of Two Boys Growing Up in the Other America 12, 187-88, 242 (1991) (chronicling how a lack of medical infrastructure played a role in shaping opportunities of two boys growing up in the Henry Horner Homes in Chicago).

[68] Mental health or competence is an issue in both the guilt and sentencing phases of capital cases. For a sample of issues raised in these contexts, see Jonathan L. Bing, *Protecting the Mentally Retarded from Capital Punishment: State Efforts Since* Penry *and Recommendations for the Future*, 22 N.Y.U. Rev. L. & Soc. Change 59 (1996).

[69] As of the mid 1990s, approximately six out of ten inmates in the nation's jails were members of racial or ethnic minority groups. Caroline Wolf Harlow, *Profile of Jail Inmates 1996 at* http://www.ojp.usdoj.gov/bjs/pub/ascii/pji96.txt (last visited Apr. 24, 1998). *See also* Bureau of Justice Statistics Criminal Offenders Statistics *at* http://www.ojp.usdoj.gov/bjs/crimoff.htm (last modified Mar. 18, 2000) (stating 65% of state prison inmates are racial or ethnic minorities). Moreover, the incidence of HIV infection in the population of prisons and jails is several times higher than in surrounding communities, even adjusted for age. F.L. Altice et al., *Predictors of HIV Infection Among Newly Sentenced Male Prisoners*, 18 J. Acquir. Immune. Defic. Syndr. Hum. Retrovirol. 444 (1998).

With high rates of incarceration but one of several factors, African Americans comprise 36% of reported AIDS cases through 1997, though only approximately 13 percent of the U.S. population is African American. *Work Group Meets on African-American Initiative for HIV Prevention*, HIV/AIDS Prevention (Centers for Disease Control and Prevention, Atlanta, Ga.), June 1998, at 2.

significantly, whether an individual is able to obtain health insurance and the scope of the benefits package provided is dependent, in part, on his or her employment. As LDF argued on behalf of itself and the National Black Women's Health Project in *Int'l Union v. Johnson Controls Inc.*,[70] historic patterns of job discrimination and poor levels of training and education combined to concentrate African American workers in unhealthy industries and the most hazardous jobs.[71] Moreover, policies that allow employers to restrict opportunities for women, rather than requiring a clean and safe work environment for all workers, have particularly adverse effects on African Americans.[72] Thus, health and employment efforts serve to reinforce one another.

III. A Historical Perspective of Legal Advocacy and Civil Rights Enforcement in the Distribution of Health Care Services

Although health has never been the top priority for legal organizations dedicated to advancing civil rights, the litigation and advocacy of a few leading groups have galvanized others to respond to the lack of equal opportunity resulting from disparities in quality of health care. The NAACP Legal Defense & Educational Fund, for example, was responsible for the landmark victory prohibiting racial segregation in health care.[73] During the late 1970s, and more recently in the 1990s, the National Health Law Program;[74] the Mental Health Law Project;[75] local legal aid and legal services offices; LDF; the Puerto Rican Legal Defense & Educational Fund (PRLDF) ;[76] other civil rights law firms;[77] and a few members of the

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[70] 499 U.S. 187 (1991).

[71] Int'l Union v. Johnson Controls Inc., 499 U.S. 187 (1991) (brief of *amici curiae*).

[72] *Id.* at 29-63.

[73] Simkins v. Moses H. Cone Mem'l Hosp., 323 F.2d 959 (4th Cir. 1963), *aff'd*, 376 U.S. 938 (1964).

[74] The National Health Law Program (NHeLP) is a national nonprofit public interest law firm that "seeks to improve health care for America's working and unemployed poor, minorities, the elderly and people with disabilities." *About NheLP: Overview at* http://www.healthlaw.org/aboutNHeLP.shtml (last modified Feb. 16, 2001).

[75] The Mental Health Law Project (MHLP) is a national nonprofit organization "founded in 1972 by lawyers and professionals in mental health and mental retardation to halt abuse and neglect in state mental hospitals and training schools and to halt the exclusion of children with disabilities from the nation's public schools." MENTAL HEALTH LAW PROJECT, Summary of Activities 9 (1990).

[76] The Puerto Rican Legal Defense and Education Fund (PRLDF) is a nonprofit legal organization "founded in 1972 to protect the civil rights of Puerto Ricans and other Latinos and to ensure their equal protection under the law." *See Puerto Rican Legal Defense and Education Fund at* http://www.igc.org/IPR (last visited Mar. 22, 2001).

[77] Other civil rights law firms that have led or participated in health care litigation, despite the fact that access to health care may not have been identified as an organizational priority, include the Asian American Legal Defense Fund and Educational Fund (AALDEF), the Center for Constitutional Rights (CCR), and the Mexican American Legal Defense and Educational Fund (MALDEF).

private bar initiated litigation challenging barriers to access and provided legal representation for national and community organizations[78] struggling to retain services and facilities for African Americans in medically underserved areas.[79] These legal organizations have put issues on the table that are otherwise neglected. Although their efforts have been significant and offer an indication of how great an impact concerted activity in this area could have, it is important to recognize that today, despite the compelling need, there is no organized civil rights health bar to carry the ball.

A. The Historical Role of the NAACP Legal Defense And Education Fund in Health Litigation

Over the years, litigation has played a central role in desegregating health facilities and challenging discriminatory practices in the delivery of health care services. Legal organizations can challenge laws, policies, programs, or practices directly and can also provide information and leverage to community groups attempting to wage their own campaigns. The outline of LDF's activities that follows is offered as indicative of the potential of litigation as a tool for challenging discriminatory barriers to accessible care.[80]

LDF's involvement in health care litigation became significant during the late 1950s and early 1960s[81] when LDF and its cooperating

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[78] The national organizations—many of which have chapters that are involved in health care issues at the local level—include, for example, the NAACP, which has a Health Division that conducts an array of outreach and training programs see *NAACP Health Division*, *at* http://www.naacp.org/health (last visited Mar. 22, 2001); the American Association of Retired Persons (AARP); the Committee for Hispanic Children and Families; the Japanese American Citizens League; MADRE; the National Association of Social Workers; the National Black Women's Health Project; the National Council of La Raza; the National Council of Negro Women; the National Minority AIDS Council; the Native American Women's Health Education Resource Center; and the Women's Policy Group, as well as a number of religiously affiliated groups, labor unions and professional organizations, such as the National Medical Association and the National Black Nurses Association.

[79] *See generally* SMITH, HEALTH CARE DIVIDED, *supra* note 15 (discussing involvement of individuals and organizations in the battle against race discrimination in the delivery of health services). There are a number of lawyers whose tireless work must be recognized. These include individuals such as Sylvia Drew Ivie, a former LDF attorney who also served as Director of the Office for Civil Rights at HHS, Jane Perkins of the National Health Law Program, and Gordon Bonnyman, who moved during the 1990s from Legal Services of Middle Tennessee to the Tennessee Justice Center.

[80] Much of the information in this section has been culled from early LDF docket sheets and annual reports. Case names and numbers were often not included and, thus, do not appear here unless the docket sheets provided sufficient information to identify and locate the case from an official source.

[81] According to an LDF docket sheet from the 1950's, as early as 1954 LDF initiated an action under the "separate but equal" standard established by *Plessy v. Ferguson*, 163 U.S. 537 (1896). LDF filed a petition in Little Rock, Arkansas on behalf of a child age eleven who had been diagnosed as mentally incompetent but was denied admission to the State Hospital for the Insane at Little Rock

attorneys led the drive to remove racial bias from the delivery of health care services, including litigation on behalf of African American medical professionals challenging denial of staff privileges and exclusion from professional medical societies.[82] In the first few years, plaintiffs suffered numerous setbacks because the courts ruled that the denial of staff privileges and exclusionary membership policies were not state action within the purview of the Fourteenth Amendment.[83]

LDF won a major victory, however, when the U.S. Supreme Court refused to review a 1963 ruling from the Fourth Circuit that held unconstitutional the "separate but equal" provision of the Hill-Burton Act of 1946.[84] The Hospital Survey and Construction Act of 1946,[85] also called the Hill-Burton Act, provided federal assistance to state governments to assess the need for health facilities, to develop state plans for the construction of hospitals and other health care facilities, and, ultimately, to modernize the facilities.[86] The text of the original statute contained language obliging recipient hospitals to make services available "to all persons residing in the territorial area of the application, without discrimination on account of race, creed, or color," but, until 1963, made an exception "in cases where separate hospital facilities [were] provided for separate population groups," so long as equitable provisions were made to ensure that services were of like quality for each such group.[87] LDF viewed *Simkins* as "a major breakthrough in the health field," noting that

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because of his race. Although the State Hospital had two wards for white children, the hospital refused admission to the young boy, arguing that the only available placement would be in a ward with insane adult men, many of whom were criminally inclined. The petition demanded admission "on the same terms and conditions and with the same treatment as all other infant incompetents." LDF Docket Sheet (on file with the author).

[82] As a 1970 LDF publication recounts, "Thurgood Marshall searched for friendly lawyers to help carry the burden of critical cases" throughout the South. NAACP Legal Defense and Educational Fund, Inc., "30 Years of Building American Justice: A Report on Services to the People of the United States by the Legal Defense Fund: 1940-1970" (New York, 1970), at 18. LDF's internship and scholarship programs enhanced the ranks of practicing civil rights lawyers across the country. *See generally* NAACP Legal Defense and Educational Fund, "Report for 1964," at 16-17 ("Expanding the Legal Corps"); NAACP Legal Defense and Educational Fund, Inc., "30 Years of Building American Justice: A Report on Services to the People of the United States by the Legal Defense Fund: 1940-1970" (New York, 1970), at 29-30, 35. The network of attorneys that formed as a result has been central to the litigation programs of organizations such as LDF. Participants in LDF's Legal Intern Program include such civil rights luminaries as Paul A. Brest, Julius L. Chambers, U.W. Clemon, Marian Wright Edelman, James E. Ferguson, II, and John W. Walker. *Id.* at 35.

[83] *See, e.g.*, Eaton v. Board of Managers of James Walker Mem'l Hosp., 261 F.2d 521 (4th Cir., 1958), *cert. denied*, 359 U.S. 984 (1959); Eaton v. Grubbs, 216 F. Supp. 465 (E.D.N.C. 1963), *rev'd*, 329 F.2d 710 (4th Cir. 1964); Hawkins v. North Carolina Dental Soc'y, 230 F. Supp. 805 (W.D.N.C. 1964), *rev'd*, 355 F.2d 718 (4th Cir. 1966). *See generally* HUBERT A. EATON, 53-60 (Wilmington, North Carolina: Bonaparte Press, 1984) (a narrative of the *Eaton* cases).

[84] Simkins v. Moses H. Cone Mem'l Hosp., 323 F.2d 959 (4th Cir. 1963), *aff'd*, 376 U.S. 938 (1964).

[85] Pub. L. No. 79-725.

[86] *See* Wing, *The Community Service Obligations of Hill-Burton Health Facilities*, 23 B.C. L. REV. 577, 583-86 (1982).

[87] *Id.*

approximately "2,000 hospitals and medical facilities in 11 Southern states had received over one-half billion dollars for new construction under the Act."[88]

The culmination of this early phase of LDF's litigation was the passage of Title VI of the Civil Rights Act of 1964, which prohibits the discriminatory use of federal funds by state and private entities. Title VI provides:

> 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.[89]

Although Title VI was ultimately interpreted as implying a cause of action by private parties,[90] the locus of responsibility for enforcement of its provisions was the federal government.[91] "Without corrective measures by the federal government," LDF's 1964 Annual Report commented, "it is conceivable that this effort [to overcome inequities in the provision of medical care] will prove even more difficult than school desegregation."[92] At this point, LDF announced its intention to press for federal enforcement of the new law.[93]

In 1966, LDF Assistant Counsel Michael Meltsner complained that federal bureaucrats were taking "an unduly restrictive view of their power and responsibility to end racial discrimination."[94] Given the "[a]dministrative tolerance of legislatively proscribed discrimination,"[95] progress also required privately initiated litigation. "Continued use of litigation by Negroes attests to the inability of the federal government to implement [the guarantee of nondiscrimination in federal programs] effectively . . . ," Meltsner wrote.[96] Then in the mid 1960s, LDF gained momentum with a series of cases on behalf of African American doctors, dentists, and nurses, who challenged the denial of staff privileges at publicly supported facilities or exclusion from professional societies.[97]

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[88] NAACP Legal Defense and Educational Fund, Inc., "30 Years of Building American Justice" (1970), at 58.

[89] 42 U.S.C. § 2000d.

[90] *See* Guardians Ass'n. v. Civil Service Comm'n, 463 U.S. 582, 593-95 (1983) (opinion of Justice White); Cannon v. University of Chicago, 441 U.S. 677, 710-16 (1979). *But see* Alexander v. Sandoval, 121 S.Ct. 1511 (2001) (holding there is no right of action to enforce disparate impact regulations promulgated pursuant to Title VI).

[91] *See* Title VI, sec. 602, 42 U.S.C. § 2000d-1.

[92] NAACP Legal Defense and Educational Fund, "Report for 1964," at 9.

[93] *Id.*

[94] Michael Meltsner, *Equality and Health*, 115 U. PA. L.REV. 22, 22 (1966).

[95] *Id.*

[96] *Id.* at 29.

[97] *See, e.g.*, Eaton v. Grubb, 329 F.2d 710 (4th Cir. 1964) (reversing lower court dismissal of suit to enjoin Wilmington, North Carolina hospital from continuing to deny staff privileges on a racially

LDF and its cooperating attorneys also moved forward with suits for the desegregation of Southern health facilities and challenges to discriminatory patient admission and treatment practices.[98]

In addition to litigation, LDF also pursued civil rights enforcement through administrative channels, working with groups such as the National Medical Association and the Medical Committee on Human Rights, though with limited success.[99] With a tone of disappointment that would be echoed in the years to come, a 1970 report commented on the effectiveness of the

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discriminatory basis and segregating patients); Hawkins v. North Carolina Dental Society, 355 F.2d 718 (4th Cir. 1966) (reversing lower court dismissal of case against state dental society); Cypress v. Newport News Gen. and Nonsectarian Hosp., 375 F.2d 648 (4th Cir. 1967) (reversing lower court dismissal of action against hospital for denying African American physicians admission to the medical staff and assigning patients to hospital rooms on a segregated basis); Bell v. Georgia Dental Ass'n, 231 F. Supp. 299 (N.D. Ga. 1964) (rejecting defendants' motion to dismiss challenge to exclusion of African Americans from membership); *see also* Foster v. Mobile Cty. Hosp. Bd., 398 F.2d 227 (5th Cir. 1968) (enjoining denial of admission to medical society).

[98] *See, e.g.*, Rackley v. Bd. of Trustees of Orangeburg Reg'l Hosp., 238 F. Supp. 512 (E.D.S.C. 1965); Flagler Hosp. v. Hayling, 344 F.2d 950 (5th Cir. 1965); Smith v. Hampton Training Sch. for Nurses, 360 F.2d 577 (4th Cir. 1966) (suit to desegregate a hospital). *See also* Marable v. Alabama Mental Health Bd., 297 F. Supp. 291 (M.D. Ala. 1969) (holding segregation and discrimination in the operation of Alabama's mental health system was violation of the Fourteenth Amendment); Small v. Hudson, 322 F. Supp. 519 (M.D. Fla. 1971) (failing to desegregate county homes for the aged violates Fourteenth Amendment). A statement of LDF activities published in the wake of *Simkins* reflects the pervasiveness of discrimination, the breadth of the challenge and the intransigence of segregationists, reporting that 1964 again underscored "the slowness with which adequate medical care is being made available to Negroes—and the gross inequities this represents":

> While southern hospital officials argued that they were not subject to Fourteenth Amendment restrictions, they continued to accept local funds raised from public sources as well as federal grants. Yet virtually all of these hospitals discriminate against Negro patients and/or physicians.
>
> On the positive side, public hospitals in three North Carolina communities agreed to desegregate after suits were brought against them. But such voluntary action, sparing costly legal proceedings, has been the exception rather than the rule. Seeking to broaden the scope of hospital litigation, the Fund sued for statewide integration of Florida's tuberculosis hospitals. . . .

NAACP Legal Defense and Educational Fund, "Report for 1964," at 9. The report concludes, "The import of these actions cannot be underrated. To halt the regrettable outflow of trained Negro physicians from the South and to secure decent care for the least healthy sector of the population are goals contingent upon equal access to public facilities." *Id. See also* Pringle v. State Tuberculosis Board of Florida, Civ. No. 1044 (N.D. Fla, filed Dec. 1964).

Docket sheets from the 1960s list a number of other cases focusing on access to health care. These include *Porter v. N.C. Hospitals Board of Control*, a challenge to the constitutionality of a North Carolina statute requiring the segregation of hospital facilities; *Carr v. Ketona County Homes*, a suit to enjoin nursing home segregation; *Curry v. City of Anniston, Anniston Memorial Hospital*, employee discharge case on behalf of a nurse; *Jenkins v. Suwannee County Hospital*, challenge to racial segregation of patients in Florida hospital; *Nesmith v. Trustees of the Rex Hospital*, hospital desegregation case in North Carolina; *Stout v. Carraway Methodist Hospital*, complaint filed to desegregate Alabama hospital; *Thornton v. Washington County General Hospital*, suit to desegregate Greenville, Mississippi hospital that had received Hill-Burton money; *Veasey v. Wake County Hospital System*, North Carolina hospital desegregation case. NAACP Legal Defense & Educational Fund, Inc., 1962 and 1967 Docket Sheets.

[99] *See* SMITH, HEALTH CARE DIVIDED, *supra* note 15, at 121-28, 143-66.

complaint procedure established pursuant to Title VI, which authorizes federal agencies to cut off funds from recipients of federal funds, including hospitals, that discriminate on the basis of race: "Over 300 complaints were filed," the text reports, "[b]ut HEW [the precursor agency to the U.S. Department of Health and Human Services] was slow in using the new authority. Before LDF filed its complaints, HEW had taken no steps at all to implement the provisions of Title VI."[100] LDF also submitted a memorandum to HEW with detailed recommendations "to effect desegregation before token compliance or noncompliance became an accepted pattern."[101]

In the 1970s, LDF co-counseled a successful challenge to discriminatory practices at six Louisiana hospitals pursuant to both Title VI and the community service obligations of the Hill-Burton Act.[102] LDF also brought a series of cases to stem the tide of facilities abandoning the nation's inner cities.[103] In *Hatcher v. Methodist Hospital*, LDF challenged a Gary, Indiana hospital's plan to build a satellite unit in a predominantly white suburb and obtained a settlement that included a commitment by the hospital to spend twenty million dollars to assure equality of services at its inner-city site.[104] The settlement also provided for the establishment of a new Family Primary Care Center and mobile health care units to travel into poor African American neighborhoods.[105]

LDF also worked with local chapters of the NAACP to prevent the closure of four municipal hospitals in New York City, bringing suit in state and federal court with mixed success.[106] Plaintiffs in *Bryan v. Koch* argued that the City's plan violated federal due process and civil rights law, state and local health planning laws, and provisions of the state constitution and

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[100] NAACP Legal Defense and Educational Fund, Inc., "30 Years of Building American Justice: A Report on Services to the People of the United States by the Legal Defense Fund: 1940-1970," (New York, 1970), at 58.

[101] *Id.* at 59. The report credits HEW for making civil rights compliance a necessary condition for the receipt of funds under Medicare. *Id.*

[102] 42 U.S.C.A. 291 *et seq.* *See* Cook v. Ochsner Found. Hosp., 61 F.R.D. 354 (E.D. La. 1972), *aff'd*, 559 F.2d 968 (5th Cir. 1977). Marilyn Rose, of the Health Law Project of the Center for Law and Social Policy, had initially served as counsel for Rosezella Cook and the other *Cook* plaintiffs. As funding for the Health Law Project declined, LDF and Sidney D. Watson, then of New Orleans Legal Assistance Corporation, agreed to co-counsel the case. Letter from M. Rose to S. Watson (Mar. 27, 1981). *See* SMITH, HEALTH CARE DIVIDED, *supra* note 15, at 168-76.

[103] *See generally* SMITH, HEALTH CARE DIVIDED, *supra* note 15, at 176-83.

[104] *Hatcher*, N.D. Ind. Civil Action No. H77-154 (1977). According to a 1980 report, the implementation of the settlement reached in *Hatcher* resulted in improved minority representation on hospital committees and its board of directors, efforts undertaken by the hospital "to assure equality in the number and skills of doctors and nurses" between the hospital's two facilities, the construction of a new, modern primary-care unit downtown, and a shuttle service for patients, patients' families, and employees. NAACP Legal Defense & Educational Fund, Inc., "The 40th Year: 1980 Annual Report," at 11.

[105] *Id.*

[106] Co-counsel in *Bryan v. Koch* included Herbert Semmel and Sandford J. Newman of the Center for Law and Social Policy, among others.

city charter.[107] These claims were roundly rebuffed.[108] The opinion by District Court Judge Abraham Sofaer rejected plaintiffs' motion for preliminary relief, evidencing little appreciation for the plaintiffs' arguments:

> [T]his is no ordinary case. It appears, rather, to be an effort by plaintiffs to use the federal courts as a last resort for delaying if not preventing the implementation by elected officials of a painful but purely political decision. Under these circumstances, to delay the closing of Sydenham [one of the hospitals] for any period—particularly for the decision-making convenience of this court—would serve to undermine the authority and governing capacity of the City's responsible officials.[109]

Although not all hospital relocation and closure cases ended in determinations against plaintiffs,[110] LDF suffered its worst setbacks in this set of cases.[111] Despite the adverse decisions on legal claims brought under Title VI, these actions were nonetheless important to community efforts to retain accessible services. For example, though the plaintiffs in *Wilmington Medical Center* challenged the adequacy of the resolution reached by the Office for Civil Rights at the U.S. Department of Health & Human Services (OCR) and the Medical Center,[112] the agreement may have been instrumental in the defendant's decision to retain its downtown facility.[113]

A decade later in 1990, LDF's health care conference and subsequent

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[107] Bryan v. Koch, 492 F. Supp. 212, 216 (S.D.N.Y.), *aff'd*, 627 F.2d 612 (2d Cir. 1980).

[108] *Id.* at 217.

[109] *Id.*

[110] *See, e.g.*, Health v. Charlotte-Mecklenburg Hosp. Auth., 681 F.2d 814 (4th Cir. 1982); *Hatcher*, N.D. Ind. Civil Action No. H77-154(1977).

[111] *See* Wilmington Med. Ctr., Inc., 491 F. Supp. 290 (D. Del. 1980), *aff'd*, 657 F.2d 1322 (3d Cir. 1981); Bryan v. Koch, 492 F. Supp. 212 (S.D.N.Y.), *aff'd*, 627 F.2d 612 (2d Cir. 1980); U.S. v. Bexar County Hosp., 484 F. Supp. 855 (W.D. Tex. 1980).

[112] *See* NAACP v. Wilmington Med. Ctr., Inc., 453 F. Supp. 280, 291-92 (D. Del. 1978) (Second Supplemental Report to Court Concerning Investigation of Plan Omega with Respect to Alleged Title VI and Section 504 Violations).

[113] Even the *Bryan v. Koch* litigation may be credited with having lasting beneficial effects. As a result of the suit, the City agreed to keep open Metropolitan Hospital, which had been targeted for closure. *See* NAACP Legal Defense & Educational Fund, Inc., "The 40th Year: 1980 Annual Report," at 11. Also notable in the 1970s and 1980s were suits brought by local legal services offices around the country against Hill-Burton facilities for their failure to provide free or below costs care in accordance with the Hill-Burton Act and the regulations promulgated to enforce the Act. *See, e.g.*, Lugo v. Simon, 426 F. Supp. 28 (N.D. Ohio, 1976) (uncompensated care suit filed by Ohio Migrant Legal Action Program and the Center for Law and Social Policy); Newsom v. Vanderbilt University, 653 F. 2d. 1100 (6th Cir. 1981) (filed by Legal Services of Nashville, the National Health Law Program, and the Southern Poverty Law Center). Legal services attorneys also brought actions against health care facilities for exclusionary admissions policies and other forms of noncompliance with the Hill-Burton community service obligations. 42 C.F.R. § 124.601 *et seq.*

report were elements of a conscious effort to rethink strategy and to focus litigation more effectively. At the same time, LDF launched cases consistent with a plan for a "multi-pronged attack." In the words of LDF's Report to the Kaiser Family Foundation, civil rights litigation should have a number of aims:

> (a) to end racial discrimination by hospitals, nursing homes, and health care practitioners, (b) to enforce the community service obligation of the Hill-Burton Act, ensuring that Hill-Burton facilities do not employ restrictive admissions practices that exclude the poorer members of their communities; (c) to ensure that low-income African Americans have access to appropriate emergency care; and (d) to enforce mandates requiring that states meet their responsibilities to secure access to services for Medicaid recipients.[114]

LDF used these goals as guideposts in its own case selection.

(a) Litigation to address racial discrimination: *Linton v. Commissioner of Health and Environment* fell in this category. Working with Legal Services of Middle Tennessee, LDF successfully challenged Tennessee's limited bed certification policy pursuant to Title VI and the Medicaid Act.[115] Under the policy, the state of Tennessee had allowed nursing homes to decertify beds formerly available to Medicaid patients to make room for privately insured patients, a practice that had an adverse and disproportionate impact on African Americans.[116]

(b) Litigation to enforce the community service obligation: LDF's continued work on behalf of community groups fighting the closure and relocation of health care facilities could be described as intended both to address racially discriminatory policies and to enforce the Hill-Burton community service obligation. In 1991, LDF, PRLDF, and the Legal Aid Society filed a complaint with the OCR against a New York-area hospital that was planning to relocate its inpatient maternal and child care services away from the medically underserved areas of Central and West Harlem.[117] Although neither the administrative proceeding nor subsequent litigation in federal court resulted in a finding of noncompliance,[118] the hospital ultimately changed course and retained a portion of the beds at its original

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[114] LDF Report, at 24.

[115] Linton v. Comm'r of Health and Environment, 779 F. Supp. 925, 931-32 (M.D.Tenn. 1990).

[116] *Id.* at 935.

[117] In Re: St. Luke's-Roosevelt Hosp. Ctr., No. 02-91-3069 (OCR complaint filed Apr. 2, 1991).

[118] In Re: St. Luke's-Roosevelt Hosp. Ctr, No. 02-91-3069 (OCR letter of findings, Mar. 24, 1998) ("insufficient" evidence found to support finding of noncompliance); Mussington v. St. Luke's Roosevelt Hosp. Ctr., 824 F. Supp. 427 (S.D.N.Y. 1993), *aff'd*, 18 F.3d 1033 (2d Cir. 1994) (case dismissed on procedural grounds).

site.[119]

(c) Litigation to ensure access to emergency care: In 1991, LDF and the NOW Legal Defense and Education Fund filed a brief of *amici curiae* with the U.S. Court of Appeals for the Fifth Circuit in *Burditt v. Sullivan.* The case involved a woman who arrived at a hospital emergency room nine months pregnant with extremely high blood pressure (210/130) and was sent to another hospital located 170 miles away.[120] The case became a vitality test of the anti-dumping law, with lawyers for state and national medical associations arguing that liability under the statute required proof of the physician's motivation. The Court adopted the position of *amici* that no proof of intent was necessary.[121]

(d) Litigation to enforce statutory mandates: LDF also brought litigation to enforce statutory mandates such as the Early and Periodic Screening, Diagnostic and Treatment Program (EPSDT), 42 U.S.C. 1396d, which requires that Medicaid providers administer screening tests for lead poisoning, among other things.[122] Similarly, with Gordon Bonnyman and others at Legal Services, LDF brought suit against the State of Tennessee for failing to provide Medicaid patients with access to obstetricians.[123] Plaintiffs withdrew the case when the state implemented Tenncare, one of the nation's earliest statewide mandatory Medicaid managed care programs, thereby changing the facts upon which the case was premised.[124]

By the close of the 1990s, however, LDF's health docket went beyond the priorities outlined in the LDF Report. LDF staff attorneys began to focus on access to the full range of reproductive health care—from obstetric to abortion services.[125] And from 1995 to 1999 LDF

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[119] In Re: St. Luke's-Roosevelt Hosp. Ctr., No. 02-91-3069 (OCR letter of findings, Mar. 24, 1998), at 6 (the hospital agreed to amend its plan to retain a small number of obstetric and neonatal beds at uptown site).

[120] *See* Brief for the Asian American Legal Defense and Education Fund et al., as *Amici Curiae* in Support of Respondent, Burditt v. Sullivan, No. 90-4611 C-42-Dec. No. 1167 (5th Cir.) (filed Jan. 9, 1991).

[121] Burditt v. Sullivan, 934 F.2d 1362 (5th Cir. 1991). *Burditt* was but one of a number of cases brought under 42 U.S.C. § 1395dd, the Emergency Medical Treatment and Active Labor Act ("EMTALA"), which was passed as part of the Consolidated Omnibus Budget Reconciliation Act of 1985, Pub.L.No. 99-272, sec. 9121, 100 Stat. 82, 164-67 (1986). Plaintiffs in these cases are most often represented by private law firms. *See, e.g.,* James v. Sunrise Hosp., 86 F.3d 885 (9th Cir. 1996); Brodersen v. Sioux Valley Mem. Hosp., 902 F.Supp. 931 (N.D. Iowa, 1995).

[122] *See* Matthews v. Coye, N.D. Cal. Civil Action No. 90-3620; *see also* Thompson v. Raiford, No. 3-92 CV 1539-R, 1998 U.S.Dist. LEXIS 2605 (N.D. Texas, Feb. 25, 1998). During the 1990s, NHeLP, local advocacy organizations, law school clinics, and law firms offering their services pro bono were responsible for launching litigation nationwide to ensure the enforcement of EPSDT. *See, e.g.,* Chischolm v. Jindal, No. 97-3274, 1998 U.S. Dist. LEXIS 2521 (E.D.La., Mar. 2, 1998) (suit brought by NHeLP, the Advocacy Center for the Elderly & Disabled, and private counsel, on behalf of disabled persons under twenty-one who were placed on a waiting list for home and community based services).

[123] Brewster v. White, M.D. Tenn. Civil Action No. 3-91-1066.

[124] *See* Tenn. Code Ann. 71-5-102 *et seq.* (1999).

[125] *See, e.g.,* In Re: St. Luke's-Roosevelt Hosp. Ctr., No. 02-91-3069 (OCR complaint filed Apr. 2, 1991) (retention of inpatient obstetric and neonatal intensive care beds); Brewster v. White, M.D.

coordinated a legal response to New York City Mayor Rudolph Giuliani's proposal to privatize the Health and Hospitals Corporation (HHC), a vital source for health care for medically underserved communities of color across the city.[126] In 1995, when the Mayor's plan was first made public, LDF was approached by the Community Advisory Board of Queens Hospital Center and numerous other community groups, organizations, and advocates, who asked for legal assistance in launching a challenge under federal civil rights laws. In response, LDF convened a process whereby community representatives and attorneys worked together to develop legal strategies. This collaborative effort spawned four state court challenges.[127] On March 30, 1999, New York's highest court issued a decision in *Campaign to Save Our Public Hospitals* and its companion case,[128] upholding the lower court ruling that the privatization plan was not authorized by the statute.[129]

In sum, although LDF's involvement in the struggle for racial equity in access to health care has been somewhat intermittent, its successes have

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Tenn. Civil Action No. 3-91-1066 (access to obstetrical care); LDF's Briefs of *Amici Curiae* in U.A.W. v. Johnson Controls, No. 89-1215 (Supreme Court, Oct. Term, 1989), Rust v. Sullivan, Nos. 89-1391, 89-1392 (Supreme Court, Oct. Term, 1990), and Planned Parenthood v. Casey. Nos. 91-744, 91-902 (Supreme Court, Oct. Term, 1991).

[126] *See generally* Charles Brecher & Sheila Spiezo, "Privatization and Public Hospitals: Choosing Wisely for New York City" (New York: Twentieth Century Fund, 1995), at 7-24 (profile of HHC).

[127] *See* Queens Hosp. Ctr. Community Advisory Bd. v. HHC, No. 123734/95 (N.Y. Sup. Ct. Queens Co., filed Sept. 27, 1995) (unsuccessful challenge based on HHC's failure to consult with community board on privatization plan, dismissed for lack of capacity to sue and standing). The petitioners in *Queens Hospital Center Community Advisory Board v. HHC* were represented by individual attorneys working *pro bono* as well as Queens Legal Services. LDF represented the citywide Council of Community Advisory Boards and other *amici curiae* when the case was on appeal. *See* "Brief of *Amici Curaie* in Support of Petitioners," Queens Hosp. Ctr. Community Advisory Bd. v. New York City Health & Hospitals Corp., No. 123734/95 (N.Y. App. Div., 1st Dept., submitted Feb. 1, 1996).

Campaign to Save Our Public Hospitals - Queens Coalition v. Giuliani, No. 97-01339 (N.Y. Sup. Ct. N.Y. Co., filed May 15, 1996) (action claiming that privatization of the hospitals was not authorized by the HHC Act, was subject to review pursuant to the Uniform Land Use Review Procedure, and required City Council approval). *Campaign to Save Our Public Hospitals* was litigated by LDF, PRLDF and the Center for Constitutional Rights (CCR). The case was consolidated with a parallel suit brought by the City Council. *See* The Council of the City of New York v. Giuliani, No. 004897-96 (Sup. Ct. Queens Co.).

David R. Jones v. City of New York, No. 96-117768 (N.Y. Sup. Ct. N.Y. Co., filed 1996) (suit by HHC Board members and others claiming both that the actions to privatize the hospitals violated procurement provisions of the City Charter and that HHC Board had failed to fulfill fiduciary responsibilities, dismissed as moot in light of favorable outcome in *Campaign*). Petitioners in *Jones* were represented by CCR, PRLDF, and Queens Legal Services.

The Comm'n on the Public's Health System v. New York City Health and Hospitals Corporation, No. 97-103242 (N.Y. Sup. Ct. N.Y. Co., filed Apr. 22, 1997) (suit against HHC for failure to issue an Environmental Impact Statement pursuant to the New York State Environmental Quality Review Act, dismissed in light of favorable outcome in *Campaign* case). Petitioners in *Comm'n on the Public's Health System* were represented by CCR, PRLDF, LDF and Carter, Ledyard & Milburn, a private firm working *pro bono.*

[128] The Council of the City of New York v. Giuliani, No. 004897-96 (Sup. Ct. Queens Co.).

[129] Council of the City of New York v. Giuliani, Campaign to Save Our Public Hospitals, No. 10763/96, slip. op. at 13 (Mar. 30, 1999).

been significant. *Simkins* and other contemporaneous cases, such as *Eaton v. Grubb*,[130] *Hawkins v. North Carolina Dental Society*,[131] and *Cypress v. Newport News General and Nonsectarian Hospital*,[132] helped to dismantle the formal trappings of racial segregation at health facilities. *Cook v. Ochsner Foundation Hospital*,[133] and even cases such as *Bryan v. Koch* and *NAACP v. Wilmington Medical Center*, which received unfavorable rulings by the courts, helped to enhance access for African Americans and stave off the departure of facilities from poor communities of color. More recently, the legal effort to stop the sale of the public hospitals in New York City demonstrated that even where traditional civil rights causes of action may be unavailing, creative legal advocacy, together with community activism, can make a difference.

B. Inadequate Civil Rights Enforcement and the Need for Leadership by Legal Advocates

Although there are multiple bases for litigation,[134] and, as suggested above, proven strategies for addressing practices that have clear civil rights dimensions, there is neither an organized civil rights health care bar nor any effective agency within the federal government to monitor or ensure compliance by health care providers.[135]

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[130] 329 F.2d 710 (4th Cir. 1964).

[131] 355 F.2d 718 (4th Cir. 1966).

[132] 375 F.2d 648 (4th Cir. 1967).

[133] 61 F.R.D. 354 (E.D. La. 1972), *aff'd*, 559 F.2d 968 (5th Cir. 1977).

[134] For an initial list of some of the statutory grounds for litigation, *see* LDF Report to the Kaiser Family Foundation, at 24-40 (discussing Title VI, 42 U.S.C. § 2000d, 45 C.F.R. Part 80; 42 U.S.C. § 1981; the community service obligation of the Hill-Burton Act, 42 U.S.C. § 291c(e) (1), 42 C.F.R. § 124.603(a); the Emergency Medical Treatment and Active Labor Act, 42 U.S.C. § 1395dd; and provisions of the Medicaid Act).

[135] The statutory framework of Title VI and institutional capacity within and outside of government for civil rights enforcement in the health care sector compare unfavorably with governing laws and the resources dedicated to ensuring compliance in the areas of employment and housing. Contrast Title VI, which prohibits discrimination by "recipients" of federal funds, including but not limited to health care providers, with Title VII of the Civil Rights Act of 1964, 42 U.S.C. § 2000e *et seq.*, and Title VIII, 42 U.S.C. § 3601 *et seq.*, which prohibit discriminatory policies and practices specifically in employment and housing, respectively. Title VII established the Equal Employment Opportunity Commission (EEOC) to receive, process and investigate claims of employment discrimination, issue "right to sue" letters, pursue voluntary resolution between parties and, where unsuccessful at conciliation, bring suit in federal court. In fiscal year 1998, the EEOC operated with a budget appropriation of $242,000,000, employed approximately 2,544 full-time employees, and managed approximately 75,000 to 80,000 charges of discrimination under Title VII and other laws governing employment discrimination. *See The U.S. Equal Employment Opportunity Commission at* http://www.eeoc.gov/overview.html (last visited Apr. 7, 1999). In contrast, the Office for Civil Rights at the U.S. Department of Health & Human Services, the federal agency with primary responsibility for civil rights enforcement in the health care sector, operated with a budget approximately one-tenth as large and employed a staff numbering in the hundreds, not thousands. U.S. Commission on Civil Rights, "Federal Title VI Enforcement to Ensure Nondiscrimination in Federally Assisted Programs,"

Just as LDF has a record of previous work on the issue, so too could histories be written of the contributions of other groups, from the National Health Law Program to the Mental Health Law Program to the National Medical Association. Racial justice in the financing and provision of health care has not, however, received sufficient attention from civil rights groups with the institutional capacity and expertise to galvanize legal resources and partner with grassroots civil rights efforts nationwide. To suggest the need for greater involvement of the legal organizations dedicated to civil rights is not to negate the contributions of the many potential allies in this struggle; indeed, a successful campaign would draw upon the unique strengths of each.[136]

There are also no effective means for government enforcement of civil rights in the health sector. Despite the fact that health care spending accounts for 14% of the United States' gross domestic product[137] and government subsidies to the health care industry account for hundreds of billions of dollars in spending,[138] discriminatory behavior is largely

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(June, 1996), at 222. Civil rights compliance in employment is also pursued by the many private firms, individual attorneys, and organizations that specialize in employment discrimination law. The National Employment Lawyers Association (NELA), for example, boasts of "a membership of more than 3,400 lawyers in all 50 states and the District of Columbia, as well as more than sixty state and local affiliates around the country." *NELA: National Employment Lawyers Association, at* http://www.nela.org/ (last visited Apr. 7, 1999). Similarly, in the area of housing, Title VIII is targeted at discrimination in the sale or rental of housing and prohibits discrimination in residential real estate-related transactions and the provision of brokerage services. 42 U.S.C. § 3601 *et seq.* Not only is enforcement pursued by the statutorily designated federal agencies working with their state and local counterparts, but since the 1960s a nationwide network of groups such as the Fair Housing Center of Greater Boston and the Open Housing Center in New York have been dedicated to ending housing discrimination. *See, e.g., National Fair Housing Advocate Online, at* http://www.fairhousing.com (last visited Apr. 7, 1999). Although health care providers and insurers are bound by generally applicable civil rights laws, such as Title VI, 42 U.S.C. § 2000d, which prohibits discrimination by recipients of federal funds, and 42 U.S.C. § 1981, which guarantees the right "to make and enforce contracts" on a nondiscriminatory basis, there are no parallel federal statutes explicitly targeted at discrimination in the provision of health care services.

[136] Potential partners include organizations representing medical professionals and consumer groups, including the African American AIDS Services and Survival Institute; the Association for Minority Health Professions Schools; the Association of Black Cardiologists, Inc.; the Association of Black Nursing Faculty in Higher Education; the Bay Area Black Consortium for Quality Health Care, Inc.; the Black Health Care Coalition, Inc.; the Minority Health Professions Foundation; the National Black Nurses Association; the National Black Women's Health Project; the National Center for the Advancement of Blacks in Health Professions; the National Dental Association; the National Medical Association; and the National Optometric Association, as well as their counterparts in the Hispanic, Asian and other communities. In addition, civil rights organizations would benefit from association with researchers and clearinghouses of information, such as the Poverty & Race Research Action Council (PRRAC), the Institute on Health Care for the Poor and Underserved at Meharry Medical College, and the American Public Health Association, as well as consumer advocacy groups such as Public Citizen and Families U.S.A.

[137] Altman & Wallack, *Health Care Spending: Can the United States Control It?*, STRATEGIC CHOICES FOR A CHANGING HEALTH CARE SYSTEM 3 (Altman & Reinhardt eds., 1996).

[138] In 1993, federal, state, and local spending accounted for 43.9% of the nation's health care expenditures. *Id.* at 12. This number actually understates the government's portion of total spending on health, however, because it fails to include off-budget items and other forms of government subsidization. *See also* PHYSICIAN PAYMENT REVIEW COMMISSION, ANNUAL REPORT TO CONGRESS (1996), at 13 (in 1994, federal and state Medicaid expenditures alone reached $144 billion).

unchecked. Government funds pour into this sector of the economy—through capital for construction, reimbursement programs such as Medicaid and Medicare, and technological and research grants—yet the allocation of these monies is largely at the discretion of private actors.[139]

Ironically, government subsidization of discriminatory behavior is precisely the problem that Title VI is intended to address. As the U.S. Commission on Civil Rights has stated, "The purpose of Title VI is to eradicate illegal discrimination in programs or activities funded by the federal government."[140] Yet, the U.S. Department of Health & Human Services disburses more than $224 billion to 700,000 recipients,[141] and federal civil rights enforcement efforts are relegated to OCR, an agency that is underfunded, inadequately staffed, and largely ineffectual.[142] Indeed, the level of financial assistance provided by HHS is approximately eight times more than that distributed by the U.S. Department of Education (DOE), and yet the budget allocated to the Office for Civil Rights at HHS is approximately one-half that of its counterpart at DOE.[143] The size of the staff at the Office for Civil Rights at HHS is only about one-third as large as DOE's.[144]

Although, as David Barton Smith has noted, the history of administrative action to enforce Title VI had a few bright moments,[145] neither the magnitude nor the organization of the federal effort has been calculated to ensure compliance. Indeed, critiques of the government's effort have been remarkably consistent over time. In 1966, for example, Michael Meltsner complained that HEW permitted formal assurances of compliance to substitute for verified changes in behavior, failed to collect comprehensive data or conduct affirmative compliance reviews, relied too heavily on complaints by victims of discrimination, inadequately investigated matters brought to the Department, and failed to sanction recipients for demonstrated violations.[146] Meltsner wrote disparagingly

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[139] *See* STARR, THE SOCIAL TRANSFORMATION OF AMERICAN MEDICINE (New York: BasicBooks, 1982) (chronicling the history of governmental accommodation to private physicians, hospitals and insurance companies).

[140] U.S. Commission on Civil Rights, "Federal Title VI Enforcement to Ensure Nondiscrimination in Federally Assisted Programs," (June, 1996), at 1 [hereinafter U.S. Commission].

[141] U.S. Commission, *supra* note 140, at 218 (relying on 1993 data).

[142] *See* U.S. Commission, *supra* note 140, at 222-23; *see also* SMITH, HEALTH CARE DIVIDED, *supra* note 15, at 166-87; Maya Wiley, "Minority Health Care Issues," in *New Challenges: The Civil Rights Record of the Clinton Administration Mid-term* (Washington, D.C.: Citizens' Commission on Civil Rights, 1995) (Corrine M. Yu & William L. Taylor, eds.), at 237-46 [hereinafter Wiley].

[143] U.S. Commision, *supra* note 140, at 218.

[144] *Id.*

[145] *See* SMITH, HEALTH CARE DIVIDED, *supra* note 15, at 128-43 (describing the work of the Office of Equal Health Opportunity during the Johnson Administration).

[146] Meltsner, 115 U. PA. L. REV., *supra* note 94, at 30-38. Kenneth Wing described HEW's performance during this early period in similar terms:

> Of over 4,000 hospitals actually visited by HEW during 1966, all but a few were cleared for participation in Medicare after brief negotiations. Although a few were

about HEW's efforts to obtain assurances of nondiscrimination from hospitals and other health institutions:

> The Department [HEW] quietly took the position . . . that execution of a facially satisfactory assurance would be accepted as sufficient unless victims of discrimination attacked the finding. A national survey of hospital discrimination announced by the Department was never carried out. Actual (as opposed to promised) compliance was converted from a precondition to receipt of funds to a distant goal which the Department would actively seek only if it received a complaint.[147]

The federal government's "[c]omplaint-oriented administration," Meltsner concluded, "is a failure."[148]

Findings of a 1987 investigation of OCR by the House Committee on Government Operations echo Meltsner's conclusions. The Report found that OCR unnecessarily delayed case processing, allowed discrimination to continue without federal intervention, routinely conducted superficial and inadequate investigations, failed to advise regional offices on policy and procedure for resolving cases, and abdicated its responsibility to ensure that HHS policies are consistent with civil rights law, among other things.[149] The House Committee criticized OCR's reluctance to sanction noncompliant recipients[150] and recommended that OCR pursue

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> noticed for hearing and twelve were actually found ineligible for federal funds, all but two were subsequently reinstated. HEW later claimed that as a result of Title VI enforcement during the initial phases of the Medicare program, nearly all of the nation's hospitals were committed to a policy of nondiscrimination. That statement was probably true in only the sense that such policies were adopted, not that they were followed.

Kenneth Wing, *Title VI and Health Facilities: Forms Without Substance*, 30 HASTINGS L.J. 137, 160 (1978) (citations omitted). Over time, however, HEW's enforcement efforts became even weaker. As Wing reported, nursing homes, which came under scrutiny later than hospitals, "received an even more cursory certification" when entering the Medicare program. *Id.*

[147] Meltsner, *supra* note 94, at 30-31 (citations omitted). *See also* GAO, "Compliance with Antidiscrimination Provision of Civil Rights Act by Hospitals and Other Facilities Under Medicare and Medicaid: Report to the Committee on the Judiciary, House of Representatives," No. B.164031(4) (1972), at 17 (finding that HEW cleared hospitals during 1966-67 "on the basis of statements of assurance of compliance and background data" submitted by the recipient institutions; "[b]ecause of this compliance procedure, [HEW] worked mainly to develop a non-discriminatory policy and a public announcement of that policy by each hospital.").

[148] *Id.* at 32. For additional discussion of HEW's early enforcement efforts, see United States Commission on Civil Rights, *HEW and Title VI: A Report on the Development of the Organization, Policies and Compliance Procedures of the Department of Health, Education, and Welfare Under Title VI of the Civil Rights Act of 1964* (1970) (criticizing agency performance).

[149] "Investigation of the Office for Civil Rights in the Department of Health and Human Services," Fifth Report by the House Comm. on Government Operations, 100th Cong., 1st Sess. (1987).

[150] *See id.* at 14, 22-25.

investigations of complaints as well as compliance reviews in more systematic ways.[151]

Nearly a decade later, an investigation by the U.S. Commission on Civil Rights revealed little improvement. As the Commission's report states, "HHS has hardly developed its Title VI enforcement program since [the creation of HHS as a separate department] in 1980."[152] HHS had promulgated no new regulations since 1980, and had published no formal guidelines for recipients of its federally assisted programs.[153] "When OCR was formed," the report commented, "it lacked individual civil rights policies, precedents, standards, and procedures necessary to operate an effective civil rights enforcement program. Efforts to establish such foundations have never been completed."[154] More specifically, the Commission made the following observations:

1. OCR's staff is small relative to the amount of federal financial assistance distributed by HHS, and the staff is not used efficiently.[155]

2. OCR devotes too great a proportion of its resources to, and its enforcement relies too heavily on, the investigation of complaints rather than other activities such as compliance reviews. OCR's activities continue to be "complaint driven."[156]

3. OCR fails to pursue strong remedies for recipients found to be in violation of Title VI.[157]

4. HHS does not systematically monitor the states' compliance with Title VI.[158]

5. Despite regulations that require recipients to maintain information necessary to determine compliance, OCR has limited routine data collection and analysis systems. "Other than the Community Service Assurance Reporting System, OCR does not regularly or systematically collect data from its recipients."[159]

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[151] *Id.* at 38.

[152] U.S. Commission, at 223.

[153] *Id.* at 223-24.

[154] *Id.* at 224-25 (citations omitted).

[155] *Id.* at 226.

[156] *Id.* at 226-28.

[157] U.S. Commission at 230-31.

[158] *Id.* at 232.

[159] *Id.* at 233-34. In 1978 Kenneth Wing called OCR's failure to produce data from which Title VI compliance could be evaluated "a major shortcoming of the Title VI enforcement program." Wing, *Title VI and Health Facilities*, 30 HASTINGS L.J. at 184. "A realistic enforcement program," wrote Wing, would require a "sophisticated inquiry into the quality and quantity of services regularly delivered to discover the kinds of racial discrimination likely to exist today." *Id.* Wing pointed out,

6. OCR "has no line authority" over the activities of HHS's operating divisions. "To the extent that staff in the operating divisions perform Title VI enforcement responsibilities, their activities are not overseen or guided by OCR. . . ."[160]

As the report states, OCR has been "overwhelmed by problems for many years" and has initiated no major new initiatives in recent years.[161]

OCR's record in the 1990s provided scant basis for optimism. For example, OCR complaint investigations continued to be "replete with problems," including delays, the lack of staff training on investigative procedures, and poor communication between OCR staff and lawyers at the Office of the General Counsel.[162] Carol G. and the St. Luke's Community Coalition filed a complaint in *In Re: St. Luke's-Roosevelt Hospital Center* alleging that the recipient's plan to reduce beds at a location in New York City not far from Harlem and to transfer all inpatient obstetric, neonatal intensive care, and pediatric beds from that site to another location further downtown had the purpose and effect of discriminating against area residents.[163] This discrimination was based on their payor status, in violation of the Hill-Burton Hospital Survey and Construction Act,[165] and its implementing regulations, 42 C.F.R. 124.601 *et seq.*, and on the basis of their race and ethnicity, in violation of Title VI and its implementing regulations.[166] Complainants submitted extensive data, studies, and expert and lay testimony to support their claims, including evidence of utilization patterns at both sites by payor status, race and ethnicity,[167] information on the health needs of the relevant communities and likely impact of the loss of services on uptown residents,[168] documentation of the inability of area

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"OCR has never attempted to compile data of this kind on a regular basis." *Id.*

[160] *Id.* at 239. David Barton Smith similarly describes OCR as an agency insulated from the operational divisions of HHS, as well as from medical service providers. More disconcerting, though, is the observation that OCR perceives itself "as a passive, neutral arbiter of disputes that should avoid taking sides." David B. Smith, *Addressing Racial Inequities in Health Care: Civil Rights Monitoring and Report Cards*, 23 J. OF HEALTH POLITICS, POL. AND LAW at 89.

[161] *Id.* at 235.

[162] *Id.* at 229-31.

[163] In Re: St. Luke's-Roosevelt Hosp. Ctr., No. 02-91-3069 (OCR complaint filed Apr. 2, 1991).

[164] *Id.*

[165] 42 U.S.C. § 291c(e). These regulations require, among other things, that "[t]he facility...take any necessary steps to insure that admission to and services of the facility are available to beneficiaries of [governmental programs such as Medicaid] *without discrimination or preference because they are beneficiaries of those programs.*" 42 C.F.R. § 124.603(c) (2) (emphasis added).

[166] 45 C.F.R. § 80.3 *et seq.*

[167] *See, e.g.*, 1988 SPARCS data contained in Letter to Messrs. Kennedy et al., OCR, Region II, from Marianne Engelman Lado, NAACP LDF (Jan. 24, 1992), at 17-20 (on file with author).

[168] *See, e.g.*, New York City Health Systems Agency, *Assessment of Maternal and Child Health Services in Upper Manhattan* (Feb. 1990); West Side/West Harlem Community Health Planning Coalition, *Report and Recommendations on Maternal and Child Health Needs in West Harlem, Morningside Heights and Manhattan Valley* (Apr. 1989).

hospitals to absorb displaced uptown patients,[169] and evidence of SLRHC's intent to change the characteristics of its patient population.[170]

In March of 1995, more than three years after OCR accepted the complaint for investigation, regional OCR officials informed complainants that their staff lacked clarity on the claim that the reduction and transfer of services discriminated against Medicaid beneficiaries in violation of the Hill-Burton community service obligation. The officials expressed the opinion that they could not apply the non-discrimination provision to the hospital relocation context without guidance from Washington.[171] Complainants sought and ultimately received a letter of clarification,[172] but by this time much of the investigation had already been performed.[173] OCR finally completed its investigation in March of 1998, nearly seven years after the filing of the complaint, and concluded that despite OCR concern "as to the possible impact of the actions of SLRHC [the recipient] on the ability of minority and Medicaid patients to access services through SLRHC," the evidence was "insufficient to support finding that SLRHC [the recipient] is in violation of Title VI or the Hill-Burton regulations."[174]

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[169] *See, e.g.*, Letter to Messrs. Kennedy et al., OCR, Region II, from Marianne Engelman Lado, NAACP LDF (Jan. 24, 1992), at 54-56 (citing letters from Harlem Hospital, Columbia Presbyterian, and Mt. Sinai) (on file with author).

[170] *See, e.g.*, Letter to Messrs. Kennedy et al., OCR, Region II, from Marianne Engelman Lado, NAACP LDF (Jan. 24, 1992), at 24-40 (on file with author); Untitled Document submitted by complainants on Dec. 23, 1991 (St. Luke's-Roosevelt Hospital Center Documents, Entry #5, at 64-65 (an excerpt from the recipients' "Market Study") (on file with author).

[171] *See* Letter to Dennis Hayashi & Ronald G. Copeland, OCR, from Marianne Engelman Lado (Mar. 9, 1995) (on file with author).

[172] *See* Letter to Marianne Engelman Lado, NAACP LDF, from George Lyons, Associate General Counsel (May 8, 1995) (on file with author).

[173] The letter from George Lyons stated, "It is OCR's position that the Hill-Burton Act community service provisions and implementing regulations prohibit discrimination against Medicaid and Medicare beneficiaries, including discrimination which results from the reduction and/or relocation of health services by a hospital with multiple sites." *Id.* at 1. Nonetheless, the letter failed to provide sufficient direction to OCR's investigators in at least two significant respects. First, the letter did not respond to complainants' request to clarify whether, in the agency's view, the community service obligation prohibited policies and practices with either the intent or effect of discriminating against Medicaid patients, versus an interpretation that would limit coverage to intentional discrimination alone. The letter of clarification merely states that "the views you [the complainants] have expressed regarding the scope of the prohibition against discrimination on the basis of form of payment will receive full consideration." *Id.* Second, although the letter indicated that OCR would assess data previously collected in the investigation to determine whether the hospital's actions were discriminatory on the basis of payor status, it did not call for a re-examination of the scope of the investigation itself to evaluate whether OCR staff were pursuing and collecting the relevant information. *Id.* Thus, the remainder of OCR's activities on this case continued to be conducted without a precise understanding of the provisions of law at issue or a plan of investigation tailored to the elements of the legal claims.

[174] Letter to Charles S. Sims et al., from Michael Carter, Region II, OCR 3/24/98, at 7 (on file with author). OCR's letter reflected serious methodological and analytic flaws, including the failures to identify what actions were being analyzed as discriminatory, to examine the impact of the challenged actions, to evaluate whether a *prima facie* case had been established, and to analyze at all either the disparate impact or the intentional discrimination claim under the Hill-Burton Act community service obligations. *See* Letter to Ronald G. Copeland, HHS, from Elaine Jones et al. (May 13, 1998) (on file with author). The letter was also flawed by its failure to state whether the recipient's plan was justified

As of the date of this publication and despite strong leadership by Tom Perez, the director of OCR during the last years of the Clinton Administration, OCR has not made significant progress on data collection, the development of an affirmative program of compliance reviews, or the development of a monitoring system to review and evaluate the performance of HHS's operating divisions with regard to civil rights concerns. There was as of the date of this publication still no systematic means for collecting racial and ethnic health care utilization data nationwide, and OCR continues to play an extremely limited role in ensuring that HHS policies are consistent with Title VI. For example, at a July 18, 1995 meeting for Medicaid advocacy groups hosted by the Health Care Financing Administration (HCFA), an agency at HHS, the leader of the HCFA team developing a model managed care encounter data system for the states to implement was asked whether the model would call for the collection of racial and ethnic data as means to assess the racial or ethnic impact of the implementation of Medicaid managed care.[175] The HCFA representative replied that, no, there were no plans to do so.[176] Instead, encounter data could potentially be matched with eligibility data, which could contain race and ethnicity.[177] The follow up question was, to paraphrase, does the eligibility data system capture race and will such cross-matching be done? The answer: No.[178] In response to a final question inquiring how HCFA planned to monitor whether the implementation of mandatory Medicaid managed care has a disproportionate impact on the basis of race or ethnicity, the official answered that she did not know.[179] Civil rights enforcement by OCR is simply inadequate.

IV. Litigation and Advocacy

There are a number of different tracks that a strategically crafted litigation and advocacy campaign might take, and, indeed, the

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by any otherwise neutral justification, the use of an inappropriate reference group in determining whether adverse impacts would be felt disproportionately by particular racial, ethnic or payor groups, and the inappropriate aggregation of data for all non-Whites when the complaint specifically alleged discrimination against African Americans and Latinos. *Id.*

[175] Medicaid Advocacy Groups/HCFA Quarterly Meeting (Washington, D.C., July 18, 1995) (author's notes) (on file with the author).

[176] *Id.*

[177] *Id.*

[178] *Id.*

[179] *Id.*

pervasiveness of the problem creates the need to choose among lines of attack. For example, during the 1990s individuals and community groups contacted LDF about a wide range of issues—from the relative difficulty faced by people of color in need of organ transplants to the question of whether Title VI or Title VII affords a remedy to the denial of hospital staff privileges.[180] LDF assistance was also sought by medical school affirmative action officers evaluating the merits and legality of ongoing programs, and by women seeking representation to challenge state regulations on the availability of services in medically underserved communities of color, on the lack of ob/gyn services in metropolitan areas and rural communities, and on the way in which unsafe working conditions threaten the reproductive health of African American women, who are disproportionately represented in unhealthy industries and hazardous jobs.[181] Each of these problems might be amenable to litigation.

This section of the article will briefly touch upon three potential, interrelated directions for advocacy. These are intended only to be suggestive, but were chosen from among the range of possibilities based on the following criteria, which should be considered by organizations when formulating a strategy about their own priorities: (1) the strategy's capacity to address barriers to access faced, particularly, by low-income communities of color; (2) possible nationwide impact; (3) flexibility, *i.e.*, whether the strategy enhances the group's ability to be responsive to community concerns; (4) whether the strategy is amenable to litigation; (5)

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[180] The answer to whether physicians, other health professionals, or their patients can challenge discriminatory denials of staff privileges pursuant to Title VI or Title VII relies, in part, on the characterization of the relationship between the health service provider and the facility. Section 604 of Title VI excludes from coverage "any employment practice of any employer, employment agency, or labor organization except where a primary objective of the Federal financial assistance is to provide employment." 42 U.S.C. § 2000d-3. Some courts, therefore, have assumed that a decision regarding staff privileges is an "employment practice" within the meaning of section 604. *See Doe v. St. Joseph's Hosp. of Fort Wayne*, 788 F.2d 411, 420-21 (7th Cir. 1986). A decision regarding the privileges of private physicians at hospitals is generally not, however, an "employment practice," in that doctors are paid by their patients or third parties and not by the facilities, and, therefore, some courts have allowed Title VI causes of action to proceed. *See Fobbs v. Holy Cross Health System Corp.*, 29 F.3d 1439, 1447 (9th Cir. 1994), *cert. denied* 513 U.S. 1127 (1995) (reversing lower court dismissal of physician's claim that health facility impermissibly discriminated against him on the basis of race); *Chowdhury v. Reading Hosp. and Medical Center*, 677 F.2d 317 (3d Cir. 1982), *cert. denied*, 463 U.S. 1229 (1983) (reversing dismissal of Title VI cause of action where board-certified physician alleged denial of staff privileges on account of race by hospital); *see also Marable v. Alabama Mental Health Bd.*, 297 F. Supp. 291, 297-98 (M.D. Ala. 1969) (finding that black patients have standing to challenge racially discriminatory hiring, training, and promotion practices because of the secondary effects felt by patients). Ironically, some courts have held that physicians lack standing to bring a cause of action pursuant to Title VII because hospitals do not act as "employers" within the meaning of that statute. *Compare Sibley Memorial Hosp. v. Wilson*, 488 F.2d 1338 (D.C. Cir. 1973) (affirming that nurse could assert Title VII claim despite absence of employment relationship with hospital) *and Pau v. Holy Redeemer Hosp.*, 547 F. Supp. 484 (E.D. Penn. 1982) (ophthalmologist denied staff privileges could bring Title VII claim), *with Beverly v. Douglas*, 591 F. Supp. 1321, 1327-28 (S.D.N.Y. 1984) (physician denied admitting privileges by hospital could not invoke Title VII).

[181] *See, e.g.*, Charlotte Rutherford, *Reproductive Freedoms and African American Women*, 4 YALE J.L. & FEMINISM 255, 275 (1992).

the strategy's potential for building coalitions across racial and ethnic lines; and (6) practicality (including cost and the likelihood of attracting financial support).

A. Advocacy to Build Mechanisms for Civil Rights Enforcement

Regulations promulgated by the Justice Department to coordinate enforcement of non-discrimination in federally assisted programs mandate that federal agencies "shall in regard to each assisted program provide for the collection of data and information from applicants for and recipients of federal assistance sufficient to permit effective enforcement of Title VI."[182] Although the collection of data is only one minimal component of an enforcement program, it is a necessary prerequisite to other activities and, thus, an important initial step for reform efforts. Indeed, the collection of comprehensive information is the first step toward development of an affirmative oversight and monitoring program to evaluate Title VI compliance by recipients of federal funds.[183]

In contrast to the regulations promulgated by HHS, which do not on their face require each recipient of federal funds to collect and report racial and ethnic data on a regular and systematic basis, enforcement of housing

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[182] 28 C.F.R. § 42.406(a).

[183] *See* U.S. Commission on Civil Rights, "Federal Title VI Enforcement to Ensure Nondiscrimination in Federally Assisted Programs," (Washington, D.C., 1996), at 246 (recommendation that OCR should implement an effective monitoring and oversight program). As others who have analyzed agency activities have indicated, institutional changes should also include greater integration of OCR into the operations of HHS, the promulgation of regulations or circulation of policy guidelines to clarify areas of ambiguity, development of pre-award review procedures that are more thorough than the collection of assurance forms, the creation of procedures for post-award compliance reviews, and improved staff training and coordination. *See* U.S. Commission, at 238-49; SMITH, HEALTH CARE DIVIDED, *supra* note 15, at 321-32; Wiley, *supra* note 142,at 245-46; House Committee on Government Operations, "Investigation of the Office for Civil Rights in the Department of Health and Human Services," at 38-39; Wing, "Title VI and Health Facilities," at 184-189. Data collection, though, is central to the identification of discrimination and additional enforcement activities. As David Barton Smith wrote:

> Have we won the war to end a racially divided and discriminatory health system? If so, knowing this would be helpful. If not, it would be helpful to know where to best use scarce resources to correct the remaining disparities. In the absence of such information, only impossible-to-conceal events such as hospital relocations invite more careful review. Title VI certification and compliance involves essentially the completion and filing of a form. There are no standard forms or procedures adopted by the state agencies responsible for Title VI certification. No analysis or summary reports are routinely completed from these efforts. While OCR conducts its own compliance reviews of facilities, budget limitations make it possible to do only a few each year in each region. Yet even for these limited federal compliance reviews, investigators have no data resources other than census figures.

SMITH, HEALTH CARE DIVIDED, *supra* note 15, at 322.

and employment discrimination laws is built on mandatory and systematic record keeping.[184]

The lack of data collection and reporting permits providers to engage in exclusionary and segregatory practices without fear of exposure or sanction. In 1978, Kenneth Wing wrote, "A major shortcoming of the Title VI enforcement program in the past has been that it produced no data from which Title VI compliance could be evaluated."[185] "To perform its functions," Wing warned, "OCR must regularly collect and analyze data indicating the kind and amount of services provided to racial minorities."[186] Two decades later, little has changed; OCR still fails to compile data in a systematic way. "Identified as a major weakness of civil rights monitoring efforts almost from their inception," David Barton Smith wrote, "efforts to improve the information available have produced little."[187]

The failure to maintain data systematically not only hampers administrative efforts to ensure compliance, but also complicates litigation by private parties. In order to establish a *prima facie* case that a recipient's policy or practice resulted in an unjustified discriminatory effect in violation of Title VI before *Alexander v. Sandoval*,[188] plaintiffs had to demonstrate that the challenged practice had a disproportionate, adverse impact on members of a particular racial or ethnic group, usually through

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[184] *Compare* 45 C.F.R. § 80.6(b) (HHS regulations requiring that recipients "keep such records and submit to the responsible Department official . . . timely, complete and accurate compliance reports *at such times, and in such form and containing such information, as the responsible Department official . . . may determine to be necessary* . . . .") (emphasis added) *with* 12 C.F.R. 27.3 (establishing the recordkeeping requirements of the fair housing home loan data system, requiring that banks attempt to obtain the race, national origin, and sex of all applicants for home loans); 29 C.F.R. § 1614.601 (Equal Employment Opportunity Commission regulations requiring agencies of the federal government to establish systems to collect and maintain accurate employment information on the race, national origin, sex, and disabilities of their employees). The regulations governing collection of equal employment opportunity data provide, in part:

> (b) Data on race, national origin and sex shall be collected by voluntary self-identification. If an employee does not voluntarily provide the requested information, the agency shall advise the employee of the importance of the data and of the agency's obligation to report it. If the employee still refuses to provide the information, the agency must make visual identification and inform the employee of the data it will be reporting . . . .
>
> (c) The information collected . . . shall be disclosed only in the form of gross statistics. An agency shall not collect or maintain any information on the race, national origin or sex of individual employees except when an automated data processing system is used in accordance with standards and requirements prescribed by the Commission . . . .

29 C.F.R. § 1614.601(b), (c).

[185] Wing, *Title VI and Health Facilities*, 30 HASTINGS L.J. at 184.

[186] *Id.*

[187] SMITH, HEALTH CARE DIVIDED, *supra* note 15, at 322.

[188] In *Sandoval*, the Supreme Court held that there is no private right of action to enforce the regulations prohibiting conduct with a disparate impact on the basis of race, color, or national origin promulgated under Title VI. Alexander v. Sandoval, 121 S.Ct. 1511 (2001).

the use of statistical evidence.[189] Thus, for example, efforts in the 1990s by LDF, CCR, the Legal Aid Society, and Legal Services attorneys to develop litigation against MCO's for allowing their physicians to refuse Medicaid recipients were delayed by the lack of data needed to calculate the racial and ethnic composition of the population of Medicaid enrollees, the individuals that are adversely affected, and the commercial enrollees, the reference group. Investigation of potential litigation now requires work with experts, such as demographers, industry analysts, and medical geographers, to fashion sound methodology for finding or estimating the necessary numbers.

In 1993, in the face of OCR's failure to develop a system for data collection,[190] the Tennessee Interfaith Coalition for Justice in Health Care filed suit seeking to compel HHS to collect data and information from recipients of federal assistance sufficient to permit effective enforcement of Title VI.[191] The plaintiffs argued that HHS had not required uniform race and ethnic data collection or reporting from health care providers produced routine reports, thereby contravening Justice Department regulations.[192] Although the case was dismissed on jurisdictional grounds,[193] administrative reform and, in particular, the development of systematic data collection processes at HHS, remains necessary to promote civil rights compliance and should be pursued by civil rights organizations through other forms of advocacy.

As David Barton Smith noted, the growth of managed care and other changes in the health sector have created a new emphasis on statistical monitoring.[194] Smith wrote:

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[189] *See* Alan Jenkins, "Title VI of the Civil Rights Act of 1964: Racial Discrimination in Federally Funded Programs," in *Civil Rights Litigation and Attorney Fees Handbook*, Vol. 10 (Clark Boardman Callaghan, 1995), 173, at 185.

[190] *See, e.g.*, U.S. Commission, at 247-48 ("OCR must institute a systematic data and information collection and analysis program to ensure that funding recipients and officials responsible for State-administered programs are fulfilling their Title VI compliance responsibilities."); Wiley, *supra* note 142, at 245 ("HHS should alter the HCFA 1450 and 1500 to collect race-based data. HHS should collect, analyze and make publicly available the data. In addition, HHS should require states to improve MMISS data collection, cross-match the data, and make it publicly available."); *see also* Perkins, "Race Discrimination in America's Health Care System," at 378 (calling for improvements in the collection of race-based health data).

[191] *See Madison-Hughes v. Shalala*, 80 F.3d 1121, at 1123 (6th Cir. 1996) (dismissing for lack of subject matter jurisdiction).

[192] *Id.*

[193] *Id.* at 1131. Plaintiffs had sued under section 706(a)(2) of the Administrative Procedure Act (APA), seeking to compel agency action unlawfully withheld. The Court of Appeals for the Sixth Circuit found that review of HHS's activities under the APA was precluded because neither the statutory scheme of Title VI nor Justice Department regulations provided meaningful standards by which to judge the sufficiency of data collection by HHS. *Id.* at 1128. Plaintiffs failed to prove that the statute or regulations set forth a mandatory legal requirement that HHS had not performed. The court found that, to the contrary, "[s]uch data collection is left to the discretion of HHS and is not subject to judicial review." *Id.*

[194] David B. Smith, *Addressing Racial Inequalities in Health Care: Civil Rights Monitoring and Report Cards*, 23 J. OF HEALTH POLITICS, POL. AND LAW 75, 94 (1998).

> Major structural changes in the organization of health care... have produced substantial changes in the way medical care is monitored. . . . In response to these changes, a massive consolidation and integration of physicians, hospitals, and other service providers is taking place. Increasingly, integrated and computerized clinical and financial information systems serve as the essential backbone of these delivery systems and health plans.
>
> These changes are reflected in the nature of the information collected by providers and purchasers of health care. Different 'report cards' have been developed to assure accountability, consumer choice, and goal-directed action. Most have undergone extensive review and development. Only minor changes in the reporting formats would be necessary for civil rights monitoring purposes.[195]

Indeed, the consolidation of the health care industry, coupled with the current drive to standardize measures to monitor and assess health services and outcomes, present new opportunities to develop and implement systems for the collection and reporting of racial and ethnic data.

B. *Impact Litigation Against Managed Care Organizations to Challenge Redlining and Other Discriminatory Practices*

The health care industry is undergoing an unprecedented transformation. The move to managed care is perhaps the most significant change,[196] and is already affecting low-income people of color, as well as the health care providers working in medically underserved communities. As researchers at the Center for Health Policy Research point out, "The growth of managed care for Medicaid patients, who are disproportionately minority has been . . . dramatic. In 1981 there were 750,000 Medicaid beneficiaries enrolled in managed care plans. By 1993 that figure has surpassed 8 million persons, a quarter of all beneficiaries."[197] As of June

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[195] SMITH, HEALTH CARE DIVIDED, *supra* note 15, at 326 (citations omitted).

[196] As the Physician Payment Review Commission recently wrote, "The managed care world is growing and changing so rapidly that many of its terms are losing their descriptive power." PHYSICIAN PAYMENT REVIEW COMMISSION, ANNUAL REPORT TO CONGRESS (1996), at 7. Currently, nearly 70 percent of privately insured workers are enrolled in some form of managed care. *Id.* at 6.

[197] Rosenbaum et al., "Civil Rights in a Changing Health Care System: Assessing Managed Care

1996, 12.8 million, or 38.6% of Medicaid beneficiaries, were enrolled in an MCO.[198] For low-income populations, and particularly those individuals with special health needs, the consequences are not yet known.[199] MCOs may cut per patient costs by limiting patient access to services,[200] and research suggests that access to health care for many low-income African Americans may actually suffer rather than improve as a result.[201]

Under Title VI of the 1964 Civil Rights Act," (Feb. 1995), at 20.

[198] PHYSICIAN PAYMENT REVIEW COMMISSION, ANNUAL REPORT TO CONGRESS (1997), at 427. The Report described the expansion of Medicaid managed care:

> In 1972, Medicaid had contracts with three plans: Health Insurance Plan of Greater New York, Kaiser Permanente in three states, and Group Health Cooperative of Puget Sound. By 1996, over 500 separate entities were serving beneficiaries. Managed care has accelerated in Medicaid during the last few years—from only about 282,000 beneficiaries in HMOs in 1981 to about 13 million beneficiaries in a variety of managed-care arrangements in 1996.

Id. at 424. *See also* "Collaborative Partnership Develops Sample Purchasing Specifications for Medicaid HIV Prevention and Care," *HIV/AIDS Prevention* (Centers for Disease Control and Prevention, June, 1998), at 17 (estimating that by June 1997 the proportion rose to approximately 48 percent of Medicaid recipients).

[199] *See* Robert H. Miller, *Healthcare Organizational Change: Implications for Access to Care and Its Measurement*, 33 HEALTH SERVICES RESEARCH 653 (1998) (analysis of initial evidence from peer-reviewed literature suggests that MCO enrollment has mixed results in terms of the frequency of hospital admissions; length of stay; utilization of costly tests and procedures and home healthcare visits; satisfaction with perceived physician interpersonal skills; and quality of care); Marsha Gold et al., *Medicaid Managed Care: Lessons From Five States*, 15 HEALTH AFFAIRS 153 (1996).

[200] In a recent article summarizing evidence from peer reviewed literature on the effects of MCO enrollment on vulnerable populations, Robert H. Miller described the typical mechanisms by which new arrangements can create disincentives for physicians to provide greater access to care:

> In one typical arrangement, an HMO contracts nonexclusively with several medical groups and IPAs whose primary care physicians act as 'gatekeepers' or otherwise manage enrollee healthcare services. The HMO capitates each physician organization for all physician services, both primary care and specialist. The HMO establishes a hospital inpatient risk pool with each physician organization, and both HMO and physician organization share savings from the risk pool if hospital days or expenditures per enrollee fall below agreed-on amounts for each type of enrollee.

Miller, *supra* note 199, at 653. As Miller further suggested, "Capitated payment to individual physicians creates concern about access to care because it contains potential incentives for underutilization if an individual physician's income varies inversely with utilization." *Id.*

[201] *See* Ware et al., *Differences in 4-Year Health Outcomes for Elderly and Poor, Chronically Ill Patients Treated in HMO and Fee-for-Service Systems*, 276 JAMA 1039, 1039 (1996) (finding that physical and mental health outcomes for poor patients were better in traditional fee-for-service systems than in managed care). The Mental Health Project of the Western Interstate Commission for Higher Education (WICHE) outlined advantages and disadvantages of managed care for Latino communities. On the positive side, managed care provides choices, competition for Medicaid patients, potentially greater accountability, and greater access to early intervention, among other things. On the negative side, WICHE analysts are concerned that MCOs generally lack knowledge of how the health care system works in Latino communities, require greater access to information and education to ensure that Latinos can navigate a consumer driven system, have an inadequate pool of bilingual and bicultural health care providers and staff, are fragmented and impersonal, and are, in other ways, a cultural mismatch. WICHE, "The Impact of Managed Care on Latino Communities," *at* http://www.wiche.edu/MentalHealth/westlink/96/feb96mcimpact.htm (last visited Jan. 17, 2001); *see also* WICHE, "Cultural Competence Standards in Managed Mental Health Care for Four

Nonetheless, the recent consolidation of health care providers and movement of patients into managed care provide a moment of opportunity for improving the organization of medical services[202] and for litigation toward that same end. Medicaid has always been a voluntary program, and thus refusals to treat poor patients of color, many of whom are either uninsured or eligible for Medicaid, have been difficult to challenge. Physicians and, to some degree, facilities, were able to rationalize patient selection decisions based on economic considerations.[203] As recipients of federal funds, MCOs, on the other hand, are also prohibited from excluding patients from participation in, denying patients the benefits of, or subjecting patients to discrimination under their programs.[204] The economic rationalization for discriminatory patient selection or treatment practices becomes more difficult, however, when MCOs become the intermediaries, since MCOs negotiate multiple contracts with employers and other purchasers of health care, each of which has its own terms and rates. Unless the state's Medicaid program pays rates that are significantly lower than any of the commercial purchasers, an MCO has little reason to offer a Medicaid enrollee restricted services or to allow its participating physicians to refuse to treat Medicaid recipients. MCOs can, thus, be held responsible for ensuring that their networks treat all enrollees equally and that patients are protected against policies and decisions that have unjustified adverse effects on the basis of race or ethnicity, such as

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Underserved/Underrepresented Racial/Ethnic Groups," *at* http://www.wiche.edu (last visited Apr. 28, 1999).

Researchers have also expressed concern about the impact of managed care on the economic viability of safety net providers in low-income communities. *See* Darnell et al., "Access to Care Among Low-Income, Inner-City, Minority Populations: The Impact of Managed Care on the Urban Minority Poor and Essential Community Providers," (Center for Health Policy Research, George Washington University, 1995); *see also* Note, *The Impact of Medicaid Managed Care on the Uninsured*, 110 HARV. L. REV. 751, 762-64 (1997).

[202] Indeed, some forms of managed care have the potential to improve access for low-income patients with chronic conditions and other vulnerable populations. MCOs can integrate care, ensure points of access by providing a choice of primary care providers, and take a more proactive approach by "identifying persons that are potentially higher cost, and treating them in an aggressive (timely and appropriate) manner." Robert H. Miller, *Healthcare Organizational Change: Implications for Access to Care and Its Measurement*, 33 HEALTH SERVICES RESEARCH 653 (1998). "Thereby organizations can profit by preventing exacerbation of conditions that could lead to high expenditures . . . ." *Id. See also* Colleen A. Foley, *The Doctor Will See You Now: Medicaid Managed Care and Indigent Children*, 21 SETON HALL LEGIS. J. 93 (1997) (managed care represents an opportunity to improve access for poor children to quality health care services).

[203] The Hill-Burton community service obligation's prohibition against discrimination on the basis of participation in a governmental third party payor program, 42 C.F.R. § 124.603(c)(1), (2), should constrain illegitimate patient selection practices, at least by the thousands of facilities that received Hill-Burton money, but it has been largely unenforced.

[204] *See* Title VI of the Civil Rights Act of 1964, 42 U.S.C. § 2000d and its implementing regulations, 45 C.F.R. § 80.3 *et seq.* Plaintiffs can challenge only acts of intentional discrimination pursuant to Title VI in federal court. Alexander v. Sandoval, 121 S.Ct. 1511 (U.S. Apr. 24, 2001). Nonetheless recipients of federal funds are still prohibited from adopting policies and practices with an unjustified disparate impact on the basis of race, color, or national origin, and such actions can be challenged under regulations 45 C.F.R. § 80.3 *et seq.* by filing complaints with OCR.

excluding Medicaid patients from treatment by participating physicians.

Disconcerting reports of MCO practices have emerged in recent years. From 1995 through 1997, LDF received complaints that physicians in one state that had implemented a mandatory managed care program for Medicaid recipients, routinely scheduled appointments with Medicaid enrollees on different days than their commercial enrollees. Tuesdays might be reserved for Medicaid managed care patients, for example, while the private enrollees of the same MCO might be invited to the office on Wednesdays and Thursdays. Similarly, a cooperating attorney in another state reported that a managed care company in a small town provided a list of physicians to its private pay enrollees that included a pediatric practice's office telephone numbers and address, but provided its Medicaid enrollees, a disproportionate number of whom were African American, a different listing, which indicated that the same physicians could only be seen at a clinic. Moreover, the Public Advocate for the City of New York released findings of a study indicating that six MCOs that offered both Medicaid and commercial plans in the New York area provided two different lists of primary care physicians—"one for Medicaid recipients and one for everyone else."[205] While some physicians were available to all enrollees, many were on the commercial list that did not appear on the list given to Medicaid patients.[206] In yet another state, a legal services office began an investigation of allegations of redlining by area MCOs. The MCOs were said to be marketing their services to Medicare recipients in white neighborhoods but avoiding African American areas, though many residents would otherwise qualify for their services.[207]

Sara Rosenbaum, director of the Center for Health Policy Research and Professor of Health Care Sciences at George Washington University, wrote, "the early evidence from managed care suggests both the existence of discriminatory practices and areas of potential concern in which greater research is warranted."[208] Specifically, she predicted the emergence of the following behaviors, which either (a) discriminate against people of color who seek to join an MCO by discouraging or otherwise evading their enrollment, or (b) discriminate among enrollees by offering or providing inferior services to African American or Latino participants:

1. An MCO may maintain shorter hours of operation and fewer locations in African American or Latino neighborhoods than in white areas.

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[205] *See* MARK GREEN, TWO LISTS: COMMERCIAL AND MEDICAID MANAGED CARE PROVIDERS (1995).

[206] *Id.* at 1.

[207] Each of the examples in this paragraph comes from the author's notes, on file with her.

[208] Sara Rosenbaum et al., *Civil Rights in a Changing Health Care System*, 16 HEALTH AFFAIRS 90, 92 (1997).

2. An MCO might use enrollment counseling practices to "cherry pick," or encourage some patients and not others to enroll. For example, a plan might tell an African American family whose child has sickle cell anemia that its providers do not offer specialized treatment for that condition.

3. An MCO might avoid contracts with providers in certain locations, thereby maintaining fewer physicians in African American or Latino neighborhoods. Provider to patient ratios, then, might be maintained at different levels in communities of color than in white areas.

4. An MCO might also apply standards in poor areas, such as a requirement that physicians be board certified, that are not applied in middle and upper class neighborhoods. For example an MCO may market its services to patients in both suburban and urban neighborhoods. In the suburb, the MCO would accept all currently practicing physicians as providers in their plan. In the city, though, it might accept only physicians with unscathed records who are board certified, and then designate a few clinics as participating providers. Thus, Medicaid recipients in the city would have more limited access than their counterparts in suburban areas.

5. An MCO might discriminate by identifying and penalizing "high cost" providers in a manner that discriminates against physicians who treat larger numbers of African American and Latino patients. For example, a plan might impose monetary sanctions or exclude a physician whose patients consistently showed higher levels of hospitalization or used more specialized care.[209]

Litigation against managed care organizations to challenge these types of practices is perhaps the most promising direction for the near future. It would build on the expertise of civil rights organizations, allow for collaboration with allies and supporters, and have an impact on an industry that is in flux and perhaps vulnerable to pressure. Litigation to challenge redlining practices or MCO policies that allow physicians to opt out of treating Medicaid enrollees but not commercial enrollees for whom the doctors are paid on a comparable pay scale, raises the specter of segregation and has the potential to generate an intuitive empathy in the general public.[210]

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[209] Rosenbaum, at 97-100.

[210] Tellingly, not all MCOs are apprised of their obligations under Title VI. In response to a demand letter sent by advocates concerned about the use of separate lists of primary care providers for commercial and Medicaid enrollees, U.S. Healthcare demonstrated ignorance of even the reporting requirements of Title VI and its regulations. *See* 28 C.F.R. § 42.106(b); 45 C.F.R. § 80.6(b)

C. *Developing New Models of Litigation to Retain and Build Medical Infrastructure in Underserved Areas*

At first blush, it is hard to imagine a role for litigation to address the dearth of medical personnel and lack of health care infrastructure in poor communities of color. Although the problem may seem compelling, the question is what, if anything, can civil rights law firms do without repeating the legal failures of the hospital closure and relocation cases?

The approach taken by LDF, PRLDF, CCR and their co-counsel in the effort to challenge the privatization of New York City Health and Hospital Corporation (HHC) facilities illustrates how national or regional civil rights organizations can develop effective responses to community concerns, once having recognized the lack of medical infrastructure in low-income communities of color as a civil rights issue. In the early months of 1995, members of the Community Advisory Board of Queens Hospital Center (the Queens CAB) learned that the Mayor of New York City had decided to privatize their hospital, along with Elmhurst Medical Center (the other public hospital in Queens), and Coney Island Hospital (in Brooklyn).[211] The future of HHC, a public benefits corporation established under state law to provide comprehensive care to all New York City residents regardless of their ability to pay,[212] was uncertain.

Although the privatization of New York's public hospitals was in some ways a local and highly political issue, the potential loss of health care accessible by poor communities of color followed a long-term trend.[213] Thus, in 1995, LDF received a number of requests to file a challenge under Title VI,[214] and its regulations.[215] In recognition of the significance of the

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(mandating the collection of data to ensure compliance). The response from U.S. Healthcare included the comment, "Our understanding of current law is that it is illegal to question our members as to their race, ethnicity and national origin data. As a result, we cannot capture or disclose the requested information." Letter from William I. Kramer, U.S. Healthcare Legal Department, to Marianne Engelman Lado et al. (Aug. 20, 1996) (on file with author).

[211] *See, e.g.*, Letters from Rory Lancman, Queens CAB, to Maria Mitchell, Special Advisor to the Mayor (Mar. 21, 1995, Mar. 27, 1995) (referring to the proposal to privatize Queens Hospital Center).

[212] N.Y. Laws Unconsol. §7382 (McKinney 1979) (Declaration of policy and statement of purpose of the HHC Act). For a profile of HHC facilities, the services they offer, and the patients served, *see* Charles Brecher & Sheila Spiezio, "Privatization and Public Hospitals: Choosing Wisely for New York City" (New York: Twentieth Century Fund, 1995); *see generally* Jerome P. Kassirer, *Our Ailing Public Hospitals — Cure Them or Close Them?* 333 NEW ENGL. J. MED. 1348 (describing unique functions of public hospitals and arguing against a move toward a "rapid and chaotic dismantling" of public hospital systems).

[213] *See* SMITH, HEALTH CARE DIVIDED, *supra* note 15, at 176-83.

[214] 42 U.S.C. § 2000d.

[215] 45 C.F.R. § 80 (prohibiting policies and practices with unjustified adverse impacts on the basis of race and ethnicity).

issues involved and the intensity of community concern, LDF offered to become involved despite its decision not to initiate litigation under Title VI and to convene a legal strategy session. In 1995, interested attorneys and community representatives gathered to brainstorm about possible procedural flaws in the Mayor's approach to the sale, as well as potential legal theories. The participants, who came from organizations with distinct constituencies and interests, agreed to continue working together where possible. Representatives from the Commission on the Public's Health System and the Campaign to Save Our Public Hospitals participated in the conversation, informed the conversation with their knowledge of the facts and their ideas, and agitated for legal action on a rapid timetable. At the same time the community groups maintained control over organizing at the grass-roots level, understanding that legal activity should not supplant other forms of advocacy that were in their domain.[216]

Through a lengthy process of consultation, research, and development, the lawyers were able to look beyond the traditional civil rights statutes and analyze a range of bases for mounting a legitimate legal challenge. Although the familiarity acquired with the particular laws that gave rise to causes of action—New York's Uniform Land Use and Review Procedure (ULURP);[217] the State Environmental Quality Review Act (SEQRA);[218] and the Health and Hospitals Corporation Act[219]—may be of little use in future cases challenging privatization or the departure of health services from medically underserved areas, the methodology developed for generating legal theories and representing and working with clients is replicable. The final proposal offered by this article, then, is that national and regional organizations continue to pursue these new models of litigation, which provide the flexibility to develop legal strategies on behalf of community residents struggling to maintain access to health care for themselves, their families and their neighbors.

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[216] The Commission on the Public's Health System in New York City worked to ascertain the veracity of claims and allegations, conducted an outreach campaign to educate the public, and provided extensive analysis of both procedural and substantive aspects of the plans and proposals as they became public. The Campaign to Save Our Public Hospitals helped to organize and assist coalitions in Brooklyn and Queens; initiated letter writing campaigns and other activities, such as an interfaith weekend of prayer; and provided information and analysis at a variety of community, administrative, and legislative forums. Both organizations produced newsletters and other documents on file with the author.

[217] New York City Charter 197-c.

[218] N.Y.S. Environmental Conservation Law 8-0101 *et seq.*, 6 N.Y.C.R.R. 617.2(1).

[219] N.Y.S. Unconsolidated Laws 7381 *et seq.*

V. Conclusion

Inequalities in access to health care continue today to exacerbate racial and ethnic disparities in morbidity and mortality rates. As the history of civil rights litigation to address discrimination and inequality in health care delivery suggests, litigation can play a significant role in challenging inequity and generating reform. Nonetheless, there is currently no organized bar nor any effective agency to monitor or ensure civil rights compliance by health care providers. Civil rights advocates now have the opportunity to make a crucial difference in whether providers and insurers and, particularly, MCOs, will take seriously their obligations under civil rights laws or, instead, whether patterns of discrimination and exclusion will continue unrecorded and unabated.