

Unequal Health Outcomes in the United States

**Racial and Ethnic Disparities in Health Care Treatment and Access,
The Role of Social and Environmental Determinants of Health,
And the Responsibility of the State**

**A REPORT TO THE COMMITTEE ON THE
ELIMINATION OF RACIAL DISCRIMINATION**

**Submitted by the CERD Working Group
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Submitted by:

Organizations

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A. Introduction and Executive Summary

The “persistent disparities” in health that were noted by the Committee in its 2001 Concluding Observations have not significantly abated. Of particular concern are widening disparities in infant mortality between black and white populations, and continuing disparities in cancer mortality, diabetes, heart disease and overall life expectancy. The US government has also failed to collect data on racial disparities in health care as required by CERD, or to provide adequate resources to federal agencies charged with monitoring compliance.

Racial and ethnic disparities in health outcomes in the U.S. are caused not only by structural inequities in our health care systems, but also by a wide range of social and environmental determinants of health. The Convention recognizes and encompasses this dual analysis in the area of public health. Article 5 of CERD provides that “States Parties undertake to prohibit and to eliminate racial discrimination in all its forms” in enjoyment of the right to “public health” and “medical care.” Public health has been interpreted by the Special Rapporteur on the Right to Health to include not only health care systems but also the underlying social and environmental factors affecting health.¹

The disproportionate lack of health insurance among minority families and children is a critical element contributing to these disparities; moreover, a substantial body of evidence demonstrates that racial and ethnic minorities receive a lower quality and intensity of health care than white patients, even when they are insured at the same levels and present with the same types of health problems.² This results, in part, from basic differences in quality of care in white vs. minority communities, inequitable distribution of health care resources, absence of a regular source of medical care for many families of color, and language barriers and cultural obstacles in the clinical encounter. Factors affecting health disparities in the social and physical environment are closely related to patterns of racial and economic housing segregation (which, as discussed in greater detail in the shadow reports on structural racism and housing segregation in the U.S., are in turn influenced by state policy). For instance, racial and ethnic minorities in the U.S. are more likely than whites to live near commercial hazardous waste facilities and other sources of air and water pollution, and to live in areas with lower quality housing, higher crime levels, lower quality public education, and limited access to healthy nutrition choices. There is also increasing evidence that race-based discrimination itself is not only emotionally hurtful, but also physiologically damaging to minority Americans, thereby leading to unique adverse health impacts.

Federal and state governments have contributed directly to health care disparities, through both historic and present day policies. Racial segregation and discrimination in

¹ Paul Hunt, *Report of the Special Rapporteur*, U.N. ESCOR, 59th Sess., Provisional Agenda Item 10 ¶ 23, U.N. Doc. E/CN.4/2003/58 (2003) (reporting on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health)(emphasis added), *available at* <http://www.unhcr.ch/Huridocda/Huridoca.nsf/0/9854302995c2c86fc1256cec005a18d7>.

² INST. OF MEDICINE, *UNEQUAL TREATMENT: CONFRONTING RACIAL AND ETHNIC DISPARITIES IN HEALTH CARE* (2003).

health care in the United States was historically a matter of government policy, endorsed in the 1896 Supreme Court's *Plessy v. Ferguson* decision upholding the constitutionality of state and local "Jim Crow" laws requiring the separation of the races. Laws such as the 1946 Hill-Burton legislation, which provided federal funding for construction of racially exclusionary hospitals, produced grossly unequal services subsidized with tax dollars, leaving a legacy of segregated health care.

Recent government policies have further perpetuated disparities in health care access for many racial and ethnic minorities. Although the government funds Medicaid and other health insurance safety net programs, recent federal laws such as the Personal Responsibility and Work Opportunity Reconciliation Act of 1996 (PRWORA), i.e. welfare reform, and the Deficit Reduction Act of 2005 (DRA) have negatively affected the health insurance status of low-income people of color. Rather than increasing access to health care for racial minorities, these policies have restricted access and are exacerbating racial disparities in health care, particularly for women and children.

The Periodic Report largely fails to address the intersection between racial and gender discrimination, contrary to the Committee's General Recommendation No. 25. For example, women of color in the United States fare significantly worse than white women in every aspect of reproductive health. African American women are nearly four times more likely to die in childbirth than white women and 24 times more likely to be infected with HIV/AIDS. These disparities result from a range of government actions and inactions, from the failure to address high rates of uninsured women of color to restrictions on public funding for sexual and reproductive health services.

U.S. environmental policies have also failed to address racial disparities in health. The key federal civil rights law addressed to "unintentional" racial disparities in government programs (Title VI of the Civil Rights Act of 1964) was recently rendered unenforceable by the U.S. Supreme Court in a 2001 decision, and Congress has not yet responded to repair the law.³ In addition, the federal Environmental Protection Agency has failed to implement the 1994 Executive Order on Environmental Justice,⁴ and its own internal complaint system for adjudicating race-based complaints is ineffective.

B. The extent of racial health disparities in the U.S.

The Periodic Report acknowledges that "a number of disparities in the prevalence of certain diseases and conditions among racial and ethnic groups . . . continue to exist."⁵

³ *Alexander v. Sandoval*, 532 U.S. 275, 293 (2001) ("Neither as originally enacted nor as later amended does Title VI display an intent to create a freestanding private right of action to enforce regulations promulgated under § 602. We therefore hold that no such right of action exists.") (footnote omitted). The case involved a Title VI challenge to Alabama state policy that administered driver's license examinations in English only. *Id.* at 275.

⁴ *Infra* Part E(2)(a).

⁵ *Sixth Periodic Reports of States Parties Due in 2005: Addendum: United States of America*, U.N. CERD, 72nd Sess., Advance Edited Version ¶ 331, U.N. Doc. CERD/C/USA/6 (2007), available at

But the report downplays the effect of health disparities on the life span of racial and ethnic minorities and fails to document how pervasive these health disparities are. For example, while the life expectancy gap between the African Americans and whites has narrowed slightly,⁶ it remains staggering. African Americans still can expect to live 6-10 fewer years than whites, and face higher rates of illness and mortality.⁷ A recent analysis of 1991 to 2000 mortality data concluded that had mortality rates of African Americans been equivalent to that of whites in this time period, over 880,000 deaths would have been averted.⁸

Racial and ethnic gaps exist across a range of health conditions beyond those identified in ¶ 258 of the U.S. report. African Americans, American Indians, and Pacific Islanders face some of the most persistent and pervasive disparities relative to whites and Asian Americans. They experience a disproportionate burden of health problems ranging from infant mortality and diabetes to cardiac disease, HIV/AIDS, and other illnesses.⁹ And while some racial and ethnic groups – such as Hispanics and Asian Americans – have better overall health status than national averages, they suffer disproportionately from some diseases such as diabetes, and tend to experience poorer health outcomes – particularly along some measures, such as cancer, infant mortality, and heart disease¹⁰ – the longer they and their descendants live in the United States.¹¹

The Periodic Report also fails to document how the health status of subpopulations within racial groups varies considerably on the basis of nationality, immigration status, and other factors. For example, Vietnamese American men have liver cancer and die from it at a rate seven times higher than that of non-Hispanic white men.¹² Vietnamese women have the highest rate of cervical cancer of any racial or ethnic group,¹³ and the rate of cervical cancer among Mexican and Puerto Rican women is two to three times that of white women.¹⁴ Native Hawaiians have the highest rate of death from breast

http://www.ohchr.org/english/bodies/cerd/docs/AdvanceVersion/cerd_c_usa6.doc [hereinafter 2007 U.S. Report].

⁶ Sam Harper et al., *Trends in the Black-White Life Expectancy Gap in the United States, 1983-2003*, 297 JAMA 1224, 1224-32 (2007).

⁷ U.S. Dep't of Health & Human Servs., 2007.

⁸ S.H. Woolf et al., *The health impact of resolving racial disparities: An analysis of US mortality data*, 94 AM. J. PUB. HEALTH 2078, 2078-81 (2004).

⁹ NAT'L CTR. FOR HEALTH STATISTICS, U.S. DEP'T OF HEALTH & HUMAN SERVS.. HEALTH, UNITED STATES, 2006 (2007) [hereinafter HEALTH, UNITED STATES, 2006].

¹⁰ *Id.*

¹¹ Yolanda Padilla et al., *Is the Mexican American "Epidemiologic Paradox" Advantage at Birth Maintained through Early Childhood?*, 80 SOC. FORCES 1101, 1101-23 (2002).

¹² Melissa McCracken et al., *Cancer incidence, mortality, and associated risk factors among Asian Americans of Chinese, Filipino, Vietnamese, Korean, and Japanese ethnicities*, 57 CA: A CANCER J. FOR CLINICIANS 190, 190-205 (2007).

¹³ NAT'L ASIAN PAC. AM. WOMEN'S FORUM, RECLAIMING CHOICE, BROADENING THE MOVEMENT: SEXUAL AND REPRODUCTIVE JUSTICE AND ASIAN PACIFIC AMERICAN WOMEN—A NATIONAL AGENDA FOR ACTION 4 (2005), available at http://www.napawf.org/file/issues/RJPolicy_Agenda.pdf.

¹⁴ Nat'l Latina Inst. for Reproductive Health, Issue Brief, Reproductive Health of Latinas in the U.S., Mar. 2002, available at <http://www.latinainstitute.org/pdf/ReproHealth.pdf>.

cancer of any racial or ethnic group, and it is the leading cause of death among Filipinas.¹⁵

Racial and ethnic health inequalities span the life course, beginning with birth outcomes and reproductive health. As the United States concedes in its report to the CERD Committee, “the Black-White gap in infant mortality widened” in the United States between 1980 and 2000.¹⁶ In fact, during that time period the black-white ratio of infant mortality increased 25 percent even as the overall infant mortality rate declined.¹⁷ In addition, African American infants are two to three times more likely than white infants to have low birth weight—a key indicator of infant mortality.¹⁸ Racial and ethnic group differences in birth outcomes persist even when socioeconomic factors are considered. For example, infant mortality rates are higher among African Americans and American Indians/Alaska Natives than among other racial or ethnic groups, even when comparing mothers at similar levels of educational attainment.¹⁹

Similarly, women of color in the United States fare significantly worse than white women in nearly every aspect of reproductive health. The U.S. has one of the highest rates of maternal mortality among western developed nations and ranks 30th in the world with respect to maternal mortality rate.²⁰ Racial disparities in maternal mortality help explain why this rate is so high. African American women are nearly four times more likely to die in childbirth than white women (30.5 vs. 8.7 deaths per 100,000 live births).²¹ These disparities have remained unchanged over the past five decades.²² This disparity is largely attributable to the fact that women of color, especially those who are low-income, disproportionately lack access to prenatal care that is essential for healthy birth outcomes.²³

Moreover, the prevalence of many sexually transmitted infections (STIs), particularly HIV/AIDS, has reached epidemic proportions among women of color in the U.S. African

¹⁵ Office of Minority Health, Dep’t Health & Human Servs., Health Status of Asian American and Pacific Islander Women, <http://www.omhrc.gov/templates/content.aspx?ID=3721> (last modified Apr. 20, 2007).

¹⁶ 2007 U.S. Report, *supra* note 5, at ¶ 258.

¹⁷ Ctrs. for Disease Control, 51 MMWR WKLY. NO. 27, 589-592 (July 12, 2002).

¹⁸ *Id.*

¹⁹ U.S. Dep’t of Health & Human Servs., 2007.

²⁰ Myra J. Tucker et al., *The Black-White Disparity in Pregnancy-Related Mortality from 5 Conditions: Differences in Prevalence and Case-Fatality Rates*, 97 AM. J. PUB. HEALTH 247, 248 (2007) (citing WORLD HEALTH ORG. (WHO), MATERNAL MORTALITY IN 2000: ESTIMATES DEVELOPED BY WHO, UNICEF, UFPA (2004)), available at http://www.who.int/reproductive-health/publications/maternal_mortality_2000/index.html.

²¹ Nat’l Ctr. for Health Statistics, Ctrs. for Disease Control, *Maternal Mortality and Related Concepts*, VITAL HEALTH STAT., Feb. 2007, at 8.

²² Tucker et al., *supra* note 20, at 247.

²³ AGENCY FOR HEALTHCARE RESEARCH & QUALITY, NATIONAL HEALTHCARE DISPARITIES REPORT, 2006, at 160 (2006), available at <http://www.ahrq.gov/qual/nhdr06/nhdr06.htm>. (stating that “the proportion women who initiated prenatal care in the first trimester was significantly lower” among all major ethnic groups compared with white women) [hereinafter 2006 NATIONAL HEALTHCARE DISPARITIES REPORT]; NAT’L INSTS. OF HEALTH (NIH), WOMEN OF COLOR HEALTH DATA BOOK: ADOLESCENTS TO SENIORS 96, 99 (3d ed. 2006) [hereinafter WOMEN OF COLOR HEALTH DATA BOOK].

American women are infected with HIV/AIDS at a rate 24 times that of white women,²⁴ and constitute 66% of the new HIV infections among women in 2005.²⁵ Black women between the ages of 25-44 were over 14 times more likely to die of HIV/AIDS than white women (23.1 v. 1.6 deaths per 100,000).²⁶ Latinas are diagnosed with AIDS at 4 times the rate of white women.²⁷ Together, African American women and Latinas account for 82 percent of reported female AIDS cases even though they are only 24 percent of the female population.²⁸ Similarly, while the number of AIDS cases declined among other racial and ethnic groups from 2001 to 2004, it doubled for Asian Pacific Islander women.²⁹ Notably, the U.S. Periodic Report scarcely mentions disparities in HIV/AIDS and completely omits a gender analysis of the problem.³⁰

C. Causes of racial health disparities in the U.S.

The causes of racial and ethnic health disparities are multifactorial. Fundamentally, they are attributable to racial discrimination and inequality of opportunity. The key structural mechanism underlying these forces is residential segregation, which powerfully shapes health resources, risks, life opportunities, and environmental exposures. These forces manifest themselves in health care settings, in interpersonal interactions, and in institutional policies and practices.

(1) Health care system access and unequal treatment

Access to quality care is critical to the health of racial and ethnic minorities in the United States. In its 2001 Concluding Observations, the Committee expressed concern about “persistent disparities in the enjoyment of . . . access to public and private health care” in the U.S.³¹ But in its 2007 report, the U.S. contends that the country’s health care system provides “strong overall care” and “[s]ubstantial progress in addressing disparities in . . . access to health care has been made over the years.”³² These assertions belie persistent and extensive racial and ethnic disparities in health care.

²⁴ Ctrs. for Disease Control, Fact Sheet, HIV/AIDS among African Americans 2 (rev’d June 2007), available at <http://www.cdc.gov/hiv/topics/aa/resources/factsheets/pdf/aa.pdf> (last viewed Oct. 31, 2007).

²⁵ Ctrs. for Disease Control, Fact Sheet, HIV/AIDS among Women 3 (rev’d June 2007), available at <http://www.cdc.gov/hiv/topics/women/resources/factsheets/pdf/women.pdf> [hereinafter HIV/AIDS among Women].

²⁶ HEALTH, UNITED STATES, 2006, *supra* note 9, 221.

²⁷ HIV/AIDS among Women, *supra* note 25, at 2; see also Kaiser Family Found., HIV/AIDS Policy Fact Sheet: Latinos and HIV/AIDS (Dec. 2006).

²⁸ HIV/AIDS among Women, *supra* note 25, at 2; see also U.S. Dep’t of Health & Human Servs., African-Americans and HIV/AIDS in the United States (June 2006), available at <http://www.hab.hrsa.gov>.

²⁹ HIV/AIDS among Women, *supra* note 25.

³⁰ 2007 U.S. Report, *supra* note 5, at ¶ 259 (merely stating that “[d]isparities were found in treatment for . . . HIV/AIDS” but failing to mention disparities in infection rates among women, immigrants, or other vulnerable populations).

³¹ *Conclusions Observations of the Committee on the Elimination of Racial Discrimination: United States of America*, U.N. CERD, 59th Sess. ¶ 19, U.N. Doc. A/56/18 (2001).

³² 2007 U.S. Report, *supra* note 25, at ¶¶ 258, 332.

The National Healthcare Disparities Report (NHDR), prepared and released annually by the U.S. Agency for Healthcare Research and Quality, is an authoritative source for the documentation of access and quality gaps. Across a range of measures of health care access, the 2006 NHDR report found that health care access and quality for people of color is overwhelmingly worse than for whites. For example, African Americans and Latinos were found to receive poorer quality care than whites on 73 percent and 77 percent of measures, respectively, and Asian Americans and American Indians received poorer care on 32% and 41% of measures, respectively.

The most significant factor contributing to these disparities is unequal health insurance coverage. Racial and ethnic minority and immigrant communities are disproportionately uninsured, making them especially vulnerable to health crises. While about 21% of white Americans were uninsured at any point in 2002, communities of color were more likely to be uninsured at any point (including 28% of African Americans, 44% of Hispanic Americans, 24% of Asian Americans and Pacific Islanders, and 33% of American Indians and Alaska Natives), and are more likely to be dependent upon public sources of health insurance.³³ Disparate rates of coverage are particularly pronounced for immigrants³⁴ and women³⁵ and children³⁶ of color.

The lack of health insurance disproportionately hurts low-income families and communities of color, in no small part because health benefits in the United States remain linked to employment. Higher-paying jobs tend to offer more comprehensive health benefit packages, while lower-paying jobs—jobs disproportionately occupied by people of color—tend to offer only limited health benefits, if offered at all, that are often accompanied by high cost-sharing arrangements with employees. Women of color are much less likely than white women to be insured through employers or to be able to afford private insurance.³⁷ Despite representing only 32% of the U.S. population, women of

³³ 2006 NATIONAL HEALTHCARE DISPARITIES REPORT, *supra* note 23.

³⁴ More than 11 million immigrants were uninsured in 2003, contributing to one-quarter of the U.S. uninsured. Between 1998 and 2003 immigrants accounted for 86 percent of the growth in the uninsured population. Employee Benefit Research Inst., *The Impact of Immigration on Health Insurance Coverage in the United States*, (Employee Benefit Research Institute Notes, 26, No. 6, 2005).

³⁵ Women of color are more likely to be uninsured than white women. 37% of Latinas, 20% African-American women, and 36% of Asian Pacific Islander women are uninsured compared to 16% of white women. KAISER FAMILY FOUND., *RACIAL AND ETHNIC DISPARITIES IN WOMEN'S HEALTH COVERAGE AND ACCESS TO CARE* (2004), *available at* <http://www.kff.org/womenshealth/7018.cfm> [hereinafter *RACIAL AND ETHNIC DISPARITIES IN WOMEN'S HEALTH COVERAGE*].

³⁶ While Hispanic children constitute less than one-fifth of children in the United States, they represent over one-third of uninsured children. Robert Wood Johnson Found., *Going Without: America's Uninsured Children* (Aug. 2005), www.rwjf.org. Among children in fair or poor health who lack insurance (nearly 570,000 children in 2002), over two-thirds are Hispanic. Urban Inst., *Fast Facts on Welfare Policy* (July 2005), www.urban.org.

³⁷ *RACIAL AND ETHNIC DISPARITIES IN WOMEN'S HEALTH COVERAGE*, *supra* note 35, at 2; JACOB'S INST. OF WOMEN'S HEALTH & KAISER FAMILY FOUND., *WOMEN'S HEALTH DATA BOOK: HIGHLIGHTS FOR WOMEN OF COLOR, A PROFILE OF WOMEN'S HEALTH IN THE UNITED STATES 2* (2001), *available at* <http://www.kff.org/womenshealth/upload/Highlights-for-Women-of-Color.pdf>. Employment-based benefits also favor families in legally recognized relationships, thereby limiting access to health care for the families of people of color living in same-sex relationships or extended family arrangements.

color constitute 51% of the uninsured.³⁸ As a result, they are disproportionately likely to rely on public health insurance or government subsidized clinics for their health care. A recent study in New York City revealed that such trends result in pervasive racial disparities in health care. Bronx Health REACH found that New York City’s public hospitals care for a much higher proportion of uninsured and publicly insured patients—who are predominantly people of color—than nearby private hospitals.³⁹ Moreover, even when uninsured patients and Medicaid recipients were seen at the same hospitals as privately insured patients, they experienced vastly different standards of care, depending on insurance status and race.⁴⁰ Especially at large academic medical centers, privately insured patients were often steered toward faculty practices, while publicly insured or uninsured patients were steered toward clinics.⁴¹ Faculty practices often have more highly trained providers, better continuity of care, 24-hour phone access, accountability to both the patient and the referring primary care provider, and more regular communication between providers.⁴² Clinics at hospitals, on the other hand, are usually staffed by a rotating set of residents who rotate in and out of clinics and are less able to provide the continuity of care that is critical, especially to patients with chronic illnesses.⁴³

Moreover, a substantial body of evidence demonstrates even when they are insured at the same levels and present with the same types of health problems that racial and ethnic minorities receive a lower quality and intensity of health care than white patients.⁴⁴ For example, insured African-American patients are less likely than insured whites to receive many potentially life-saving or life-extending procedures, particularly high-tech care, such as cardiac catheterization, bypass graft surgery,⁴⁵ or kidney transplantation.⁴⁶ Black cancer patients fail to get the same combinations of surgical and chemotherapy treatments that white patients with the same disease presentation receive.⁴⁷ And African-American heart patients are less likely than white patients to receive diagnostic procedures, revascularization procedures, and thrombolytic therapy, even when they have similar characteristics as white patients.⁴⁸ Even routine care suffers. Black and Latino patients are less likely than whites to receive aspirin upon discharge following a heart attack, to receive appropriate care for pneumonia, and to have pain – such as the kind resulting

³⁸ WOMEN OF COLOR HEALTH DATA BOOK, *supra* note 23; RACIAL AND ETHNIC DISPARITIES IN WOMEN’S HEALTH COVERAGE, *supra* note 35, at 2.

³⁹ BRONX HEALTH REACH, SEPARATE AND UNEQUAL: MEDICAL APARTHEID IN NEW YORK CITY 21 (2005).

⁴⁰ *Id.* at 19, 24.

⁴¹ *Id.* at 24.

⁴² *Id.*

⁴³ *Id.*

⁴⁴ INST. OF MEDICINE, UNEQUAL TREATMENT (2003).

⁴⁵ Kaiser Family Found. & Am. Coll. of Cardiology, Racial/Ethnic Differences in Cardiac Care: The Weight of the Evidence, Oct. 2002.

⁴⁶ A.C. Klassen et al., *Relationship Between Patients’ Perceptions of Disadvantage and Discrimination and Listing for Kidney Transplantation*, 92(5) AM. J. PUBLIC HEALTH (2002).

⁴⁷ INST. OF MEDICINE, UNEQUAL TREATMENT (2003).

⁴⁸ Kaiser Family Found. & Am. Coll. of Cardiology, *supra* note 45.

from broken bones – appropriately treated.⁴⁹ Moreover, minorities are more likely to receive undesirable treatment than whites, such as limb amputation for diabetes.⁵⁰

(2) Social and community-level determinants of health

Disparities in access to quality health care are not the only factors that contribute to the racial and ethnic gaps in health status. The neighborhood and community contexts in which people live powerfully shape access to health care resources and health behaviors, as well as health risks. Many people of color live in neighborhoods that are largely segregated from white Americans, and the communities in which they reside differ significantly on a number of important social, economic, and environmental conditions in ways that can negatively influence health. For instance, African Americans remain the most segregated racial/ethnic group in America, followed by Latino/as.⁵¹ Importantly, individuals do not have equal opportunities to select the communities they reside in. The practice of segregation is reliant on government policy as well as institutional discrimination in the real estate and housing finance market and individual acts of discrimination.⁵² (*see e.g.* Reports of the CERD Working Groups on Structural Racism and Housing Discrimination and Segregation) People of color are also exposed to additional health risks in the form of racism and discrimination, which present stressors that are exacerbated by residential segregation.

Neighborhood factors influence health in several ways. They exert direct effects on both physical and mental health through neighborhood conditions such as levels of crime and violence, overcrowding, and environmental exposures. Neighborhood conditions also indirectly influence health, in that the conditions of neighborhoods can either support or discourage healthy behaviors, such as exercise, proper nutrition, and the development of strong social supports. The quality and availability of health care resources, as noted above, also varies by neighborhood racial, ethnic, and socioeconomic status, with low-income communities and communities of color often facing a relative paucity of such resources. For example, in New York City, areas with high concentrations of African Americans, Latinos, and Asian Americans disproportionately face serious shortages of primary care physicians.⁵³ A comparison of two New York City zip codes illustrates the racial disparities in health challenges facing people of color in the City. The overwhelming majority of East Harlem residents are people of color—55% are Hispanic, 33% African American, and 6% Asian American. East Harlem’s rates of ambulatory care sensitive (ACS) conditions—common preventable conditions that can be treated through standard disease management and primary care—are far higher than the citywide

⁴⁹ INST. OF MEDICINE, *UNEQUAL TREATMENT* (2003).

⁵⁰ *Id.*

⁵¹ JOHN ICELAND ET AL., U.S. CENSUS BUREAU, *RACIAL AND ETHNIC RESIDENTIAL SEGREGATION IN THE UNITED STATES: 1980-2000* (2002).

⁵² DOUGLAS S. MASSEY & NANCY DENTON, *AMERICAN APARTHEID* (1993).

⁵³ THE OPPORTUNITY AGENDA, *DANGEROUS AND UNLAWFUL: WHY OUR HEALTH CARE SYSTEM IS FAILING NEW YORK AND HOW TO FIX IT* 47 (2006), *available at* <http://www.opportunityagenda.org> (click on “Policy Center” then “Policy Briefs & Publications”).

average: an average rate of 2,007 cases per 100,000 residents annually.⁵⁴ For example, 13% of the zip code's residents have diabetes, compared to 9% citywide.⁵⁵ However, there are only six primary care physicians for every 10,000 residents.⁵⁶ This means that a large proportion of East Harlem residents must either travel to other neighborhoods for care or not receive any at all. Given other barriers, including inadequate access to health insurance, cultural and language barriers, and increased time and distance to care, many are likely to go without care. Alternatively, on the Upper East Side, where over four in five residents, or 82%, are white, 6% are Hispanic, 6% are Asian American, and 3% are African American there are 67 primary care physicians for every 10,000 people, or more than ten times the number found in East Harlem.⁵⁷ In other words, New York City neighborhoods with the greatest health care needs are predominantly made up of people of color and have the least access to primary care physicians. Such patterns of racial disparities in health care violate Article 5 of CERD.

To the extent that neighborhoods suffer from inadequate public services and health care, lower performing schools, poor access to jobs and employment, lack of public investment, unhealthy living conditions, and higher rates of disorder, crime, and incarceration—all problems that disproportionately burden communities of color—the opportunity for individuals to advance economically, and therefore improve health status, is constrained.⁵⁸

For example, majority-minority communities are less likely than predominantly white communities to have major grocery stores with fresh, low-cost fruits and vegetables, making it more difficult for residents of these communities to maintain healthy diets, even if they desire to do so.⁵⁹ Over half (56%) of the residents in neighborhoods with commercial hazardous waste facilities are people of color.⁶⁰ Crowding, substandard housing, elevated noise level, decreased ability to regulate temperature and humidity, and elevated exposure to noxious pollutants and allergens, such as lead, smog, and dust mites, are all common in poor, segregated communities. Lack of recreational facilities, such as parks, gymnasiums, and swimming pools in segregated neighborhoods can discourage

⁵⁴ Analysis by Steve Schreiber of SPARCS and New York State Area Health Education Center data; analysis by The Opportunity Agenda based on 2004 New York State Area Health Education Center and 2000 U.S. Census Bureau data obtained via <http://infoshare.org> (last visited July 13, 2006); Dep't of Health & Mental Hygiene, NYC Community Health Profiles (2d ed. 2006), at <http://www.nyc.gov/html/doh/html/data/data.shtml>.

⁵⁵ DEP'T OF HEALTH & MENTAL HYGIENE, TAKE CARE EAST HARLEM: NYC COMMUNITY HEALTH PROFILES 1-16 (2d ed. 2006), at <http://www.nyc.gov/html/doh/downloads/pdf/data/2006chp-303.pdf>.

⁵⁶ Analysis by The Opportunity Agenda based on 2004 New York State Area Health Education Center and 2000 U.S. Census Bureau data obtained via <http://infoshare.org> (last visited July 13, 2006).

⁵⁷ Analysis by The Opportunity Agenda based on 2004 New York State Area Health Education Center and 2000 U.S. Census Bureau data obtained via <http://infoshare.org> (last visited July 13, 2006).

⁵⁸ JOINT CTR. HEALTH POLICY INST. & POLICYLINK, BUILDING STRONGER COMMUNITIES FOR BETTER HEALTH (2004), available at <http://www.policylink.org/pdfs/JointCenter-Communities.pdf>.

⁵⁹ Kimberly Morland et al., *The Contextual Effect of the Local Food Environment on Residents' Diets: The Atherosclerosis Risk in Communities Study*, 92(11) AM. J. PUB. HEALTH (2002).

⁶⁰ ROBERT D. BULLARD ET AL., TOXIC WASTES AND RACE AT TWENTY: 1987-2007 (2007) (report prepared for the United Church of Christ Justice and Witness Ministries).

and impede physical exercise.⁶¹ Low levels of funding, poor quality instruction, and the poor physical conditions of schools in segregated neighborhoods influence property values, turnover in teacher employment, and student learning, so poor schools serving people of color present mutually reinforcing disadvantages for students, teachers, and neighborhood residents alike.⁶² Moreover, segregated communities face higher rates of crime and violence, which directly affect physical health by increasing risk for injury and death, directly impact mental health, and indirectly affect health by limiting economic investment and increasing social isolation.⁶³ And an inequitable criminal justice system, in which African Americans, Latinos, and American Indians are disproportionately penalized and imprisoned, and in which impoverished urban communities with high rates of arrest and imprisonment do not develop the social bonds and networks needed to maintain health, further exacerbates health disparities.

(3) The health effects of race based discrimination, bias, and racial prejudice

In addition to structural inequality perpetuated by residential segregation, there is increasing evidence that race-based discrimination is not only emotionally hurtful, but physiologically damaging to people of color. A growing body of research, using innovative methods, is beginning to uncover the toll. For example, over 2,000 participants in a recent national survey were asked about their experiences with discrimination and their health histories. Researchers found that everyday discrimination was associated with a variety of health conditions, such as chronic cardiovascular, respiratory, and pain-related health issues. Filipinos reported the highest level of discrimination, followed by Chinese-Americans and Vietnamese-Americans.⁶⁴ Perceived race-based discrimination is positively associated with smoking among African Americans, and smokers find the experience of discrimination more stressful. Additionally, repeated subjection to race-based discrimination is associated with higher blood pressure levels and more frequent diagnoses of hypertension among African Americans.⁶⁵ In another study, black women who reported that they had been victims of racial discrimination were 31 percent more likely to develop breast cancer than those who did not.⁶⁶ Experiences of racial discrimination also are associated with poor health among Asian Americans.

New models offer mechanisms to explain how racialized behavior and institutions affect health. These models “locate health disparities in the external influences of social space

⁶¹ David R. Williams & Chiquita Collins, *Racial Residential Segregation: A Fundamental Cause of Racial Disparities in Health*, 116 PUB. HEALTH REP. 405, 405-16 (2001).

⁶² MARY W. FILARDO ET AL., BUILDING EDUC. SUCCESS TOGETHER (BEST), GROWTH AND DISPARITY: A DECADE OF U.S. PUBLIC SCHOOL CONSTRUCTION (2006).

⁶³ Jeffrey Morenoff et al., *Neighborhood Inequality, Collective Efficacy, and the Spatial Dynamics of Urban Violence*, 39 CRIMINOLOGY 517, 517-60 (2001).

⁶⁴ G.C. Gee et al., *A nationwide study of discrimination and chronic health conditions among Asian Americans*, 97 AM. J. PUB. HEALTH 1275, 1275-82 (2007).

⁶⁵ Vickie M. Mays et al., *Race, Race-Based Discrimination, and Health Outcomes Among African Americans*, 58 ANN. REV. OF PSYCHOLOGY (2007).

⁶⁶ Teletia R. Taylor et al., *Racial Discrimination and Breast Cancer Incidence in Black Women*, 166(1) AM. J. EPIDEMIOLOGY (2007).

and the internal effects of body and brain functioning.”⁶⁷ They suggest that harmful effects of discrimination are the result of chronic experiences of race-based discrimination, both actual and perceived. These process set into motion physiological responses (e.g. elevated blood pressure and heart rate, production of biochemical reactions, hypervigilance) that deteriorate health. Importantly, these stressors can be both chronic and acute. Chronic stress associated with financial and caretaking pressures, fear of violent victimization, grief, and frustration and anger brought on as a reaction to persistent discrimination have deleterious health effects that continue even when residents from segregated neighborhoods are relocated to safer residential areas.⁶⁸ Chronic stress can lead to increased risk for coronary health disease, chronic inflammation, cognitive impairment, substance abuse and the erosion of mental health, and has demonstrable health effects on other mental and physical processes.⁶⁹

Race-related stress operates to wear down health in several ways. From a developmental perspective, the influence of negative environments associated with structural racism and residential segregation has a profound and negative effect on health and development of young children. Childhood exposure to conditions of violence, coupled with poor education, and negative social connectedness—particularly early childhood exposure to these conditions – is associated with changes in brain functioning and physiological responses. Unhealthy social spaces associated with segregation serve as the “structural lattice” for maintaining discrimination. In addition, intergenerational and life-span effects of race discrimination suggest that the health effects of racism carry forward over time in individuals and across generations. For example, low birth weight, which is more prevalent among African Americans and American Indians than other groups, is shaped by the mothers’ socioeconomic conditions, and affects the long-term health of the developing infant, despite generally improving opportunities and better environments for minorities.⁷⁰

D. The role of government policies in creating and perpetuating health disparities

(1) Historical actions of government: segregated and unequal health care

Up until the 1950s, racial segregation and discrimination in health care in the United States was a matter of government policy.⁷¹ The Supreme Court’s 1896 decision in *Plessy v. Ferguson* endorsed the development of state and local “Jim Crow” laws requiring the separation of the races. These laws were applied to health care institutions, schools, and public accommodations. They produced grossly unequal services subsidized with tax dollars. Hospital accommodations were so limited for blacks in 1946 that only 45 percent of all black babies were born in a hospital in contrast to 87 percent of all white

⁶⁷ Mays et al., *supra* note 65.

⁶⁸ Douglas S. Massey et al., *The Continuing Consequences of Segregation: Family Stress and College Performance*, 85(5) SOC. SCI. Q. (2004).

⁶⁹ Mays et al., *supra* note 65.

⁷⁰ *Id.*

⁷¹ DAVID B. SMITH, *HEALTH CARE DIVIDED: RACE AND HEALING A NATION* (1999).

babies.⁷² In the North, where state and local Jim Crow laws did not require segregation, tolerance of discrimination in housing and in the admissions and referral practices of physicians and hospitals assured almost an equivalent degree of segregation and unequal care. In Chicago for example, 71 percent of all black deaths took place at Cook County Hospital, while the sixty voluntary hospitals that provided the care for the vast majority of Chicago's white population accounted for less than 8 percent of the city's black hospital deaths.⁷³

The 1946 Hill-Burton legislation provided federal funding for construction of racially exclusionary hospitals, representing the only piece of federal legislation in the 20th century to explicitly condone such practices. Additionally, increasing federal support of medical training and research after World War II helped reinforce the long established pattern of relying on low-income minority communities for "clinical material." The often cited example of the resulting abuses, the Tuskegee syphilis study, assigned black patients without their knowledge to a non-treatment group so that the natural course of the disease could be observed. Tuskegee was not a rogue criminal enterprise, but rather reflected commonly accepted and unquestioned practices supported by the federal government that continued unchallenged until the 1970s.⁷⁴ The legacy of these practices continues to undermine the trust of minority communities in the medical services they receive.

The autonomy assured individual physicians and the pervasive reliance on voluntary organizations in the provision of medical services helped further insulate publicly funded discriminatory practices in health care against any social accountability. While federal and local public facilities were required to begin to integrate in the 1950s, the bulk of hospital care and federal support went to private voluntary organizations outside the reach of federal laws and regulations. It was not until 1964 that the federal courts ruled that these voluntary hospitals, by virtue of their participation in state Hill-Burton planning and funding, were an "arm of the state" and thus subject to the equal protection provisions of the Fourteenth Amendment.⁷⁵

Racial discrimination in the provision of health care in the U.S. has gender specific impacts on women of color. The U.S. government has a long history of seeking to control the reproductive lives of women of color. An egregious example of such coercion occurred in the early and middle part of the 20th century, when thousands of African American, Puerto Rican, and Native American women were sterilized without their full knowledge or informed consent.⁷⁶ In the 1970s the federal government used

⁷² Albert W. Dent, *Hospital Services and Facilities Available to Negroes in the United States*, 18 J. NEGRO EDUC. 326, 326-32 (1949).

⁷³ City of Chi. Comm'n on Human Relations, *Distribution of Negro Births and Deaths in Chicago Hospitals*, 1954 (1955).

⁷⁴ JAMES H. JONES, *BAD BLOOD: THE TUSKEGEE SYPHILIS EXPERIMENT* (1981).

⁷⁵ *Simkins v. Moses H. Cone Memorial Hospital*, F.2d 959 (4th Cir.1963), cert. denied, 376 U.S. 938 (1964).

⁷⁶ See generally DOROTHY ROBERTS, *KILLING THE BLACK BODY: RACE, REPRODUCTION AND THE MEANING OF LIBERTY* (1997); Iris Lopez, *Agency and Constraint: Sterilization and Reproductive Freedom Among Puerto Rican Women in New York City*, in *SITUATED LIVES: GENDER AND CULTURE IN EVERYDAY*

threats and misinformation to coerce thousands of Native American women into being sterilized shortly after childbirth.⁷⁷ Also during this time period, federal officials tricked illiterate African American women on welfare to consent to the sterilization of their teenage daughters, and they ignored informed consent procedures to perform hysterectomies on young Native American women.⁷⁸ Doctors performing Medicaid deliveries refused to deliver babies of black women unless they first agreed to be sterilized.⁷⁹ Underlying these policies are racial stereotypes that portray women of color as breeding a deviant, social underclass of poor Americans—in effect, blaming women of color for racial inequalities.⁸⁰

The government's coercive policies continue today through aggressive promotion of the use of long-acting and irreversible forms of contraception among poor women.⁸¹ In the 1990s, the FDA approved the hormonal contraceptives Depo-Provera and Norplant for marketing in the United States, despite the lack of data on long-term safety and widespread concerns about lack of user control.⁸² In addition to policies rewarding women on welfare cash bonuses if they chose Norplant, courts have required insertion of these contraceptives as a condition of probation or in resolution of child-protection proceedings, regardless of women's autonomy and the risks to their reproductive health.⁸³ Moreover, evidence has shown that while the government funds insertion of long-acting contraceptives, it has not provided for timely removal upon the user's request.⁸⁴ The 1996 welfare reform law perpetuated the government's efforts to control the reproductive capacity of women of color by making it easier for states to impose "family caps" on limits on welfare recipients.⁸⁵ Under these rules, which have been adopted by 22 states, a state pays no additional benefits to families on welfare if a mother gives birth to a child

LIFE 157-75 (Louise Lamphere et al. eds. 1997); Charlotte Rutherford, *Reproductive Freedoms and African-American Women*, 4 YALE J.L. & FEMINISM 255 (1992); Berta E. Hernandez, *To Bear or Not to Bear: Reproductive Freedom as an International Human Right*, 17 BROOKLYN J. INT'L L. 309 (1992); Pamela D. Bridgewater, *Reproductive Freedom as Civil Freedom: The Thirteenth Amendment's Role in the Struggle for Reproductive Rights*, 3 J. GENDER & JUSTICE 401 (2000).

⁷⁷ AM. INDIAN POLICY REVIEW COMM'N, REPORT ON INDIAN HEALTH: FINAL REPORT TO THE AMERICAN INDIAN POLICY REVIEW COMMISSION (1976); Jael Silliman et al., UNDIVIDED RIGHTS: WOMEN OF COLOR ORGANIZE FOR REPRODUCTIVE JUSTICE 111-12 (2004).

⁷⁸ Rutherford, *supra* note 76, at 273-74.

⁷⁹ *Id.*

⁸⁰ See generally ROBERTS, *supra* note 76, at 1-7.

⁸¹ Madeline Henley, Comment, *The Creation and Perpetuation of the Mother/Body Myth: Judicial and Legislative Enlistment of Norplant*, 41 BUFF. L. REV. 703 (1993); Bonnie Steinbock, *The Concept of Coercion and Long-Term Contraceptives*, in COERCED CONTRACEPTION? MORAL AND POLICY CHALLENGES OF LONG-ACTING BIRTH CONTROL (1996); Catherine Albiston & Laura Beth Nielsen, *Welfare Queens and Other Fairy Tales: Welfare Reform and Other Reproductive Controls*, 38 HOWARD L.J. 473, 489-511 (1995).

⁸² Henley, *supra* note 81, at 758-63.

⁸³ Melissa Burke, *The Constitutionality of the Use of the Norplant Contraceptive Device as a Condition of Probation*, 20 HASTINGS CONST. L.Q. 207, 218 (1992); Albiston & Nielsen, *supra* note 81, at 489.

⁸⁴ Henley, *supra* note 81, at 762-63 (discussing doctors' refusal to remove Norplant against the wishes of Native American women who had experienced unpleasant side effects).

⁸⁵ Anna Marie Smith, *The Sexual Regulation Dimension of Contemporary Welfare Law: A Fifty State Overview*, 8 MICH. J. GENDER & L. 121, 168-69 (2002).

during a period in which the family was eligible for public assistance.⁸⁶ Unlike policies in any other government social welfare program, “the family cap constitutes a penalty for child-bearing that is imposed solely upon the poor.”⁸⁷ This penalty disproportionately burdens women of color because they constitute the majority of welfare recipients. And notably, many of the same states imposing family cap sanctions also restrict public funding for abortion,⁸⁸ thereby creating a double-bind for low-income women of color.

(2) Ongoing government policy

(a) Retreat from monitoring and enforcement of racial disparities in health care

The United Nations’ approval of the Convention in 1965 coincided with the high water mark of efforts by the United States government to eliminate discrimination in health services. However, the protections that began to be put in place with the passage of the 1964 Civil Rights Act and with the implementation of the Medicare program in 1966 were subsequently eroded by a cumulative series of government decisions reflecting a basic policy shift away from a commitment to fulfilling its obligations under the Convention.

For instance, an initial executive branch decision exempted physicians receiving federal Medicare funds from compliance with the nondiscriminatory provisions of Title VI of the 1964 Civil Rights Act. Thus, unlike health facilities, physicians have never been compelled either to comply with the Act or submit signed assurances of nondiscrimination. This failure to enforce compliance by physicians responsible for patient care has undermined the goal of Title VI. In addition, more than forty years since the nondiscriminatory requirements were imposed by law on any party receiving public funding to provide health care, the federal executive branch has failed to collect any information to monitor compliance.

The U.S. has also failed to budget adequate resources to the Office for Civil Rights (OCR), the federal agency responsible for enforcing compliance with Title VI. No resources have ever been allocated to a testing program, which is generally the only way to effectively enforce compliance. Little staffing is available and the budget is limited. Consequently, OCR has shifted in its role from what was initially envisioned as one of advocacy, investigation and enforcement to that of a passive arbitrator of disputes and a hollow bureaucratic shell.

Federal legislation and decisions of the executive branch to pursue market-related approaches in health care threaten to erode most of the previous gains in reducing racial disparities in access to care. Government policies have increased financial incentives for

⁸⁶ See, e.g., Cal. Welf. & Inst. Code §11450.04 (West 2001); Conn. Gen. Stat. Ann. §17b-112 (West 2001); Fla. Stat. Ch. 414.115 (2000); Ga. Code Ann. §49-4-186 (2000).

⁸⁷ Smith, *supra* note 85, at 175-76.

⁸⁸ See Dep’t of Health & Human Servs., Office of the Assistant Sec’y for Planning & Evaluation, *Setting the Baseline: A Report on State Welfare Waivers* tbl. III (1997), http://aspe.hhs.gov/hsp/isp/waiver2/TABLE3.htm#N_1_ (“Family Cap Policies by State”).

providers to expand services to affluent and predominantly white geographic areas and reduce services to low-income and predominantly minority areas. Earlier federal government efforts to plan and pay for services based on need have been abandoned. The Medicare program that originally provided a single standard of universal coverage for the elderly has been fragmented into a complex assortment of plans that create financial incentives for low- and moderate-income consumers to select different plans than the more affluent. The effect is an increasing re-segregation of care and greater racial disparities in services. For example, Medicare beneficiaries must now choose between health plans that offer: 1) limited choice and access to providers but fewer out of pocket costs or, 2) more open access and choice of providers but more out of pocket costs. The inevitable effect of this is to redistribute beneficiaries across these different Medicare plans on the basis of income, undermining the original purpose of this Civil Rights era legislation to assure an equal standard of care to all.

(b) Ongoing government policies that restrict health care access

Recent government policies have further perpetuated disparities in health care access for many racial and ethnic minorities – namely, in health care coverage. Research has shown that individuals with health insurance – regardless of race, income, education or other socioeconomic factors – have greater access to the health care system and are more likely to receive care when needed.⁸⁹ Yet, federal policies such as the Personal Responsibility and Work Opportunity Reconciliation Act of 1996 (PRWORA), i.e. welfare reform, and the Deficit Reduction Act of 2005 (DRA) have negatively affected the health insurance status of many in our most vulnerable populations, especially low-income people of color. These policies have altered eligibility requirements, enrollment processes, and cost-sharing limits for the country’s primary health coverage safety-net programs, Medicaid and the State Children’s Health Insurance Program (SCHIP).

(i) The Personal Responsibility and Work Opportunity Reconciliation Act of 1996 (PRWORA)

PRWORA reformed the welfare system in the United States in several key ways:

Increased the Administrative Burden: PRWORA de-linked eligibility for Medicaid from other means-tested programs such as food stamps, requiring a separate enrollment form. In general, social programs have a higher take-up rate when enrollment is automatic.⁹⁰ The burden of completing a separate application process for enrollment in Medicaid or SCHIP jeopardizes health care benefits for many minority children and families. Additionally, burdensome procedures for Medicaid eligibility disproportionately impact low-income women of color, who are more likely to be eligible for Medicaid than white

⁸⁹ M. Lillie-Blanton et al, *The Role of Health Insurance Coverage in Reducing Racial/Ethnic Disparities in Health Care*, 24(12) HEALTH AFFAIRS (2005).

⁹⁰ Janet Currie, *The Take-Up of Social Benefits* (National Bureau of Economic Research, NBER Working Paper #10488, May 2004).

women. Latinas are twice as likely and African Americans are nearly three times as likely to be on Medicaid as white women.⁹¹

Raised Eligibility Barriers: Another key element of PRWORA is the implementation of a five-year ban on eligibility for Medicaid, SCHIP, and other public benefits programs for recent immigrants.⁹² Prior to this act, permanent legal immigrants had the same access to public benefits as did U.S. citizens.⁹³ Now legal immigrants arriving after August 22, 1996, are restricted from federally-matched Medicaid and SCHIP coverage for their first five years in residence. Five years after passage of the law, non-elderly immigrant adults have experienced a 36 percent decline in coverage.⁹⁴ The same law has had a similar effect on immigrant children, who are more likely to be uninsured than citizen children. From 1995 to 2005, the uninsured rate for citizen children declined from 19 to 15 percent as Medicaid and SCHIP enrollment increased by 17 percent. In contrast, during this same time period the uninsured rate for documented immigrant children increased from 44 to 48 percent, while Medicaid and SCHIP coverage declined by 17 percent.⁹⁵

The five-year bar also deters many eligible immigrant women from enrolling in Medicaid for fear of jeopardizing their immigration status. As a result of this policy, by 2001 Medicaid coverage had decreased by almost half among both recent immigrant women *and* long-standing resident women, even though the latter group is Medicaid-eligible.⁹⁶ Accordingly, many immigrant women cannot access vital preventative and primary care such as prenatal and postpartum care, family planning services and supplies, and treatment for reproductive system cancers.⁹⁷ As a result, this policy contravenes the CERD Committee's General Recommendation 30, which urges States parties to "refrain[] from denying or limiting [non-citizens'] access to preventive, curative and palliative health services."⁹⁸

Recognizing the importance of providing health coverage to the immigrant population, 21 states and the District of Columbia now use their own funds to offer basic health services to documented children and pregnant women who otherwise would be prohibited from enrolling in a public health insurance program due to the five-year limit.⁹⁹ States that traditionally have large populations of immigrants, such as California, New York, and

⁹¹ RACIAL AND ETHNIC DISPARITIES IN WOMEN'S HEALTH COVERAGE, *supra* note 35, at 2.

⁹² H.R. REP. NO. 104-725 (1996).

⁹³ Dana P. Goldman et al., *Immigrants and the Cost of Medical Care*, 25 HEALTH AFFAIRS 1700, 1700-11 (2006).

⁹⁴ Leighton Ku, Ctr. on Budget & Policy Priorities, Reducing Disparities in Health Coverage for Legal Immigrant Children and Pregnant Women, Apr. 27, 2007, <http://www.cbpp.org/4-20-07health2.htm> [hereinafter Ku, Reducing Disparities in Health].

⁹⁵ *Id.*

⁹⁶ Rachel Benson Gold, *Immigrants and Medicaid after Welfare Reform*, GUTTMACHER REP. ON PUB. POL'Y, May 2003, at 6-9, available at <http://www.guttmacher.org/pubs/tgr/06/2/gr060206.html> (last viewed Sept. 11, 2007).

⁹⁷ Ku, Reducing Disparities in Health, *supra* note 94, at 2; *see supra* notes 82-91 and accompanying text.

⁹⁸ *Discrimination Against Non Citizens*, U.N. OHCHR CERD, Gen. Rec. No. 30 ¶ 36, Jan. 10, 2004.

⁹⁹ *Id.*

Texas, are among them,¹⁰⁰ but the federal policy has left many immigrant women and children in other states without any health insurance whatsoever. Over the past 15 years, immigrants are increasingly locating in “new growth” states, such as Arkansas, North Carolina, and Iowa, which do not offer state-funded coverage to these populations, leaving them vulnerable to health risks.¹⁰¹

(ii) The Deficit Reduction Act of 2005 (DRA)

On February 8, 2006, President Bush signed into law the Deficit Reduction Act, imposing the most significant set of changes to Medicaid’s coverage structure since its 1965 enactment. The negative impacts of this legislation, described below, are disproportionately experienced by low-income people of color.

Burdensome Citizenship Documentation Requirement: Prior to the DRA, citizens could verbally confirm their citizenship status and the status of their children when either applying or re-determining eligibility for the program. Legal residents were required to provide written proof of legal status. Despite the absence of evidence that non-citizen immigrants were securing Medicaid by falsely declaring themselves to be U.S. citizens, Congress added a provision in the DRA to require proof of U.S. citizenship and identity, such as a U.S. passport or birth certificate, when applying for Medicaid coverage or seeking to renew coverage.¹⁰²

Recent data shows that the new law has the biggest impact on poor U.S. citizens, especially African Americans.¹⁰³ This group disproportionately lacks documentation of their citizenship and the financial means to afford the application fees for a duplicate birth certificate or passport.¹⁰⁴ In Alabama, after six months of implementing the requirement, 3,500 children previously enrolled in Medicaid were disenrolled for failure to meet the documentation requirement. Of those children, 2,100 (60%) were African American.¹⁰⁵

The DRA citizenship documentation requirement creates delay and difficulty for women who lack such documentation to secure it in time to access time-sensitive prenatal care

¹⁰⁰ MEREDITH I. KING, CTR. FOR AM. PROGRESS, IMMIGRANTS IN THE U.S. HEALTH CARE SYSTEM: FIVE MYTHS THAT MISINFORM THE AMERICAN PUBLIC (2007), *available at* http://www.americanprogress.org/issues/2007/06/pdf/immigrant_health_report.pdf.

¹⁰¹ Ku, Reducing Disparities in Health, *supra* note 94.

¹⁰² Donna Cohen Ross, Ctr. on Budget & Policy Priorities, New Medicaid Citizenship Documentation Requirement Is Taking A Toll: States Report Enrollment is Down and Administrative Costs are Up, Feb. 2007, <http://www.cbpp.org/2-2-07health.htm>.

¹⁰³ Donna Cohen Ross, Ctr. on Budget & Policy Priorities, Medicaid Documentation Requirement Disproportionately Harms Non-Hispanics, New Data Show: Rule Mostly Hurts U.S. Citizen Children, Not Undocumented Immigrants, July 2007, <http://www.cbpp.org/7-10-07health.htm> [hereinafter Documentation Requirement Disproportionately Harms Non-Hispanics].

¹⁰⁴ For example, 9% of African American adults lack either a passport or birth certificate. Leighton Ku et al., Ctr. on Budget & Policy Priorities, Survey Indicates Deficit Reduction Act Jeopardizes Medicaid Coverage for 3 to 5 Million U.S. Citizens, Feb. 17, 2006, <http://www.cbpp.org/1-26-06health.htm>.

¹⁰⁵ Data from the Alabama Medicaid Agency as of May 21, 2007.

through Medicaid.¹⁰⁶ Twenty states have exercised the prerogative now available under the DRA to deny prenatal care unless a woman provides documentation of citizenship.¹⁰⁷ This delays care that negatively impacts both women of color and their children. The lack of prenatal care is an important contributing factor to maternal and infant mortality, which disproportionately affects African Americans.¹⁰⁸

The Committee's General Recommendation 30 recommends that States parties "respect the right of non-citizens to an adequate standard of physical and mental health by, inter alia, refraining from denying or limiting their access to preventive, curative and palliative health services."¹⁰⁹ Though it applies only to U.S. citizens seeking to enroll or renew enrollment in Medicaid, the DRA's citizenship documentation requirement has a discriminatory effect on non-citizens' access to health services through Medicaid. In the years since the law was enacted, eligible, long-standing resident immigrants have been deterred from enrolling in Medicaid because they believe they must produce proof of citizenship, rather than merely proof of legal status, in order to qualify.¹¹⁰ The U.S. government has failed to conduct information campaigns or take other measures to correct this belief.

Increased Out-of-Pocket Costs: Before the DRA, Medicaid enrollees paid limited out-of-pocket costs for the health care services they received. The law formerly ensured that cost sharing protections were in place that reflected the limited incomes and considerable health care needs of Medicaid enrollees. For these reasons, state Medicaid agencies were prohibited from charging premiums and enrollment fees for most program enrollees, and cost-sharing was prohibited for children.¹¹¹

The DRA gives states increased flexibility to impose premiums, cost-sharing, or both. First, the law removed the statutory bar on denying care to Medicaid recipients who are unable to afford cost-sharing. The effect is that states may now charge Medicaid recipients for certain services and deny them health care if they are unable to pay for the gap in coverage. Second, states can now choose to impose premiums on children and parents if their family income is above 150 percent of the federal poverty level, or

¹⁰⁶ Adam Sonfield, *The Impact of Anti-Immigrant Policy on Publicly Subsidized Reproductive Health Care*, GUTTMACHER POL'Y REV., Winter 2007, at 7, 9.

¹⁰⁷ *Id.*

¹⁰⁸ Ctrs. for Disease Control, Press Release, Pregnancy-Related Mortality Surveillance—United States, 1991-1999 (2003), available at <http://www.cdc.gov/od/oc/media/pressrel/fs030220.htm> (last visited Sept. 11, 2007) (showing that women who receive no prenatal care are three to four times more likely to die in childbirth than women who receive any prenatal care); WOMEN OF COLOR HEALTH DATA BOOK, *supra* note 23, at 99, 103 (showing that Native Americans and African Americans, who are the least likely to receive prenatal care in the first trimester, have the highest rates of infant mortality).

¹⁰⁹ *Discrimination Against Non Citizens*, *supra* note 98, at ¶ 36.

¹¹⁰ Sonfield, *supra* note 106 (noting the enrollment rate among legal residents fell from 26% to 17% between 1994 and 2005); see also Leighton Ku, Ctr. on Budget & Policy Priorities, Why Immigrants Lack Adequate Access to Health Care and Health Insurance, Sept. 2006, <http://www.migrationinformation.org/Feature/display.cfm?id=417>. (explaining that immigrants believe they must show proof of citizenship, not just legal status, when applying for Medicaid).

¹¹¹ Kaiser Family Found., Deficit Reduction Act of 2005: Implications for Medicaid (Feb. 2005).

roughly \$31,000 for a family of four.¹¹² Third, states can also require prepayment of premiums before one can be enrolled in Medicaid, thereby deterring low-income families from enrolling. Fourth, Medicaid coverage can be terminated – even for children – if premiums are not paid with 60 days of the due date.¹¹³ In summary, this provision poses financial burdens for low-income families and creates the risk that some enrollees will not seek services when necessary.

These provisions have a disproportionate impact on people of color, in violation of the U.S. government's obligations under the CERD. African Americans, Hispanics, and American Indian/Alaska Natives are twice as likely to have family incomes less than 200 percent of the federal poverty level as whites. In 2005, this equated to a little more than \$39,000 for a family of four.¹¹⁴ It is therefore more likely that people of color will be unable to meet the premium and cost sharing requirements authorized by the DRA and effectively be denied access to health care as a result.

Lower Benefit Standards: Medicaid law provides two categories of benefits: mandatory or optional. Mandatory benefits formerly included inpatient and outpatient physician services, and physician and preventive services included in Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) services for individuals under 21. The DRA took away the category of mandatory benefits, allowing states to replace the existing Medicaid benefit package for children and certain other groups with “benchmark” coverage, or coverage comparable to that provided by the largest commercial HMO in the state.

By 2015, the Congressional Budget Office estimates that the benefit reduction will affect 1.6 million enrollees, many of whom are people of color.¹¹⁵ Although Medicaid’s EPSDT benefits have created more uniform and comprehensive coverage for children across all states, the DRA changes make it likely that children will not receive these necessary services. Providing more limited benefits could result in unmet health care needs and make it more difficult for beneficiaries to access care, as they are likely to have difficulty paying for uncovered services.¹¹⁶

(iii) Bans on public funding for abortion

Federal public funding for abortions is prohibited except in extremely limited circumstances. This includes most notably the Hyde Amendment, a federal restriction which bans public funding for abortions except in cases of life endangerment, rape, and incest.¹¹⁷ Thus, while the Medicaid program generally funds all “medically necessary”

¹¹² Exemptions from cost-sharing are only available for the very poor--families with incomes below 100% of the federal poverty level, or in the case of premiums, 150% of the poverty level. S. Rosenbaum, et al., *The Deficit Reduction Act of 2005: An Overview of Key Medicaid Provisions and Their Implications for Early Childhood Development Services*, Commonwealth Fund (Oct. 2006).

¹¹³ *Id.*

¹¹⁴ Kaiser Family Foundation, *Key Facts: Race, Ethnicity, & Medical Care* (Jan. 2007).

¹¹⁵ Kaiser Family Found., *Deficit Reduction Act of 2005*, *supra* note 111.

¹¹⁶ Meredith I. King, Ctr. for Am. Progress, *The SCHIP Shortfall Crisis: Ramifications for Minority Children* (Mar. 2007).

¹¹⁷ P.L. No. 105-78 § 509 (1997).

services,¹¹⁸ medically necessary abortions are excluded. Although states have the power to extend state Medicaid funding for abortion beyond what is covered by federal Medicaid, the majority of states (33) fail to provide such coverage.¹¹⁹ As a result, the majority of women who rely on publicly funded health care programs have no access to medically necessary abortions unless they are able to cover the entire cost out-of-pocket. Women of color are disproportionately impacted by this policy scheme because they are more likely to rely on Medicaid. Women who cannot obtain funding must either delay their abortions, which increases both the cost of the procedure and risks to a woman's health, or forego the procedure altogether.¹²⁰

The Hyde Amendment applies not just to Medicaid, but to all programs administered by the Department of Health and Human Services, including the Indian Health Service (IHS). IHS is the primary source of reproductive health care for most Alaskan Native/American Indian women—a population that is less likely than other Americans to have private health insurance or to be able to afford out-of-pocket costs for an abortion.¹²¹ Women receiving health insurance through federal prisons are also subject to the federal ban on funding for abortions. Since 1987 women in federal prisons have been denied public funding for an abortion except in the cases of rape or life endangerment.¹²² This policy has a disparate impact on women of color because they comprise over 70% of women incarcerated in federal prisons.¹²³

In addition to the fact that the federal government does not provide funding for medically necessary abortions to those reliant on public health programs, individual states, often those with higher than average rates of poverty and populations of color, are enacting onerous restrictions intended to make access to abortion more difficult.¹²⁴ For instance,

¹¹⁸ 42 U.S.C. § 1396 (2000).

¹¹⁹ Guttmacher Inst., *State Policies in Brief: An Overview of Abortion Laws* (Oct. 1, 2007), available at http://www.guttmacher.org/statecenter/spibs/spib_OAL.pdf.

¹²⁰ S. Henshaw & L. Finer, *The Accessibility of Abortion Services in the United States, 2001*, 35 PERSP. ON SEXUAL & REPRODUCTIVE HEALTH 16, 23 (2003) (showing that between 18-35 % of women who would have had an abortion if funding had been available instead carried their pregnancies to term, and that 22 % of women on Medicaid who had abortions in the second trimester would have done so in the first if Medicaid provided funding).

¹²¹ Heather D. Boonstra, *The Heart of the Matter: Public Funding of Abortion for Poor Women in the United States*, GUTTMACHER POL'Y REV. Winter 2007, at 12, 13-14, available at <http://www.guttmacher.org/pubs/gpr/10/1/gpr100112.html>.

¹²² *Id.* at 14.

¹²³ LAWRENCE A. GREENFELD & TRACY L. SNELL, U.S. DEP'T OF JUSTICE, BUREAU OF JUSTICE STATISTICS SPECIAL REPORT: WOMEN OFFENDERS (rev'd Oct. 2000), available at <http://www.ojp.gov/bjs/pub/pdf/wo.pdf>.

¹²⁴ The ten poorest states in order of largest percentage of persons below poverty level are: Mississippi, Louisiana, New Mexico, West Virginia, Texas, Arkansas, Alabama, Kentucky, Oklahoma and South Carolina. The District of Columbia ranks between Louisiana and New Mexico. U.S. Census Bureau, *Percent of People Below Poverty Level in the Past 12 Months (For Whom Poverty Status Is Determined): 2005*, 2005 AM. CMTY. SURVEY tbl. R1701 available at <http://www.census.gov/compendia/statab/ranks/rank34.htm>. Of these ten states, eight (MS, LA, TX, AL, AK, KY, OK, SC) have passed significant restrictions on abortion, including legislation to outlaw abortion. NARAL PRO-CHOICE AMERICA, WHO DECIDES?: THE STATUS OF WOMEN'S REPRODUCTIVE HEALTH IN THE UNITED STATES 1-2 (2007), available at http://www.prochoiceamerica.org/choice-action-center/in_your_state/who-decides/introduction/who_decides_2007_full.pdf.

Mississippi is the poorest state in the country and has the highest African American population; it also has enacted some of the most restrictive abortion laws in the United States.¹²⁵ The lone abortion clinic in Mississippi is three hours from the rural Delta, where the poorest women in the state live. The mandatory 24 hour waiting period in Mississippi¹²⁶ adds the expense of lodging or a second round trip from the Delta to Jackson to the costs of obtaining the procedure, which makes the costs of obtaining an abortion even more prohibitively high. Combined with the public funding restrictions on abortion,¹²⁷ some of these women cannot afford the costs of travel and lodging to reach the clinic and pay for the procedure. Moreover, even for women who are able to pull together the financial resources to travel to the clinic, the difficulty of doing so will likely delay her abortion procedure, either increasing the health risks associated with the procedure, or perhaps preventing her from being able to obtain an abortion at all.¹²⁸

(iv) Title X funding for reproductive and sexual health care

Many women of color who do not have private insurance and are not eligible for Medicaid rely on the Title X program for their reproductive health care.¹²⁹ The Title X program provides funding to clinics across the country who provide reproductive services (excluding abortion) without charge or on a sliding scale based on income. The Title X program serves 6.6 million low-income women, 40% of whom are women of color.¹³⁰ For many years, however, Congress has failed to fund the Title X program at the level necessary to meet the reproductive health needs of its target population. Funding is now

¹²⁵ In 2007, 98% of Mississippi counties had no abortion provider. Eighty-six percent of Mississippi women lived in these counties. In the South census region, where Mississippi is located, 32% of women having abortions traveled at least 50 miles, and 10% traveled more than 100 miles. In Mississippi, the following restrictions on abortion were in effect as of August 2007: the parents of a minor must consent before an abortion is provided; a woman must receive in-person state-directed counseling that includes information designed to discourage her from having an abortion, and then wait 24 hours before the procedure is provided; public funding is available for abortion only in cases of life endangerment, rape, incest or fetal abnormality. Abortion is covered in insurance policies for public employees only in cases of life endangerment, rape or incest, or fetal abnormality. See Guttmacher Inst., *State Facts about Abortion: Mississippi* (2006), <http://www.guttmacher.org/pubs/sfaa/print/mississippi.html> (last viewed Sept. 11, 2007).

¹²⁶ Miss. Code Ann. § 41-41-33 (2007).

¹²⁷ § 41-41-91.

¹²⁸ After the 24-hour waiting period law was enacted, second trimester abortions rose by 53 % among women closest to an in-state provider while the number of abortions declined overall. Ted Joyce & Robert Kaestner, *The Impact of Mississippi's Mandatory Delay Law on the Timing of Abortion*, FAM. PLAN. PERSP., Jan./Feb. 2000, available at <http://www.guttmacher.org/pubs/journals/3200400.html> (last viewed Oct. 26, 2007).

¹²⁹ In most states, women with dependent children will qualify for Medicaid if they earn less than 67% of the federal poverty level for working parents, while women would be able to obtain services at a Title X funded clinic if they have an income up to 250% of the federal poverty level. Jennifer J. Frost et al., *Estimating the Impact of Serving New Clients by Expanding Funding for Title X* (Guttmacher Institute, Occasional Report No. 33, Nov. 2006), available at <http://www.guttmacher.org/pubs/2006/11/16/or33.pdf>.

¹³⁰ Guttmacher Inst., *Facts in Brief: Title X and the U.S. Family Planning Effort 3* (1997), available at <http://www.guttmacher.org/pubs/ib16.html>.

61 percent lower in inflation-adjusted dollars than in 1980.¹³¹ The challenge of meeting a rising demand for services with fewer financial resources has left a majority of Title X-supported clinics unable to offer a full range of contraceptives.¹³²

Title X clinics are also struggling to meet the health needs of new and hard-to-reach populations, including rising numbers of non-native English speakers and immigrants ineligible for Medicaid.¹³³ Outreach, including language services and culturally appropriate materials, is critical for ensuring that vulnerable groups of women receive care. For example, many Asian Pacific Islander (API) women avoid HIV testing because they lack a translator.¹³⁴ The delay in testing leads to later diagnoses that make treatment more difficult or increase the possibility of HIV transmission. Notably, the HIV infection rate among API women has doubled in recent years even as the general rate declines.¹³⁵

(c) Failure of US law to protect racial and ethnic minorities from disproportionate environmental burdens

In 1987 a report published by the United Church of Christ, *Toxic Wastes and Race in the United States*, found that race was the most significant predictor in forecasting where the nation's commercial hazardous waste facilities are sited. Moreover, a subsequent study published in the *National Law Journal* in 1992 exposed significant racial disparities in environmental enforcement. Among other things, the study revealed a "racial divide in the way the U.S. government cleans up toxic waste sites and punishes polluters. White communities see faster action, better results and stiffer penalties than communities where blacks, Hispanics and other minorities live."¹³⁶ The study also found that communities of color overall, regardless of income, received less protection than white communities. Penalties collected under the hazardous waste laws like the Superfund law were about 500 percent higher in white communities than in communities of color. Overall, penalties collected in white communities were nearly 50 percent higher than in communities of color, providing a weaker deterrent to would-be violators of the law. According to the *National Law Journal* study, it takes 20 percent longer to get contaminated sites that are in neighborhoods of color added to the official list of sites to be cleaned up with Superfund money.¹³⁷

¹³¹ Rachel Benson Gold, *Stronger Together: Medicaid, Title X Bring Different Strengths to Family Planning Effort*, GUTTMACHER POL'Y REV., Spring 2007, at 13, 15, available at <http://www.guttmacher.org/pubs/gpr/10/2/gpr100213.html> [hereinafter Gold, *Stronger Together*].

¹³² Frost et al., *supra* note 129, at 11-12 (citing a 2003 survey which found that two-thirds of agencies operating Title X-supported clinics were unable to stock certain contraceptive methods due to cost).

¹³³ Gold, *Stronger Together*, *supra* note 131, at 18; Cynthia Dailard, *Challenges Facing Family Planning Clinics and Title X*, GUTTMACHER REP. ON PUB. POL'Y, Spring 2001, available at <http://www.guttmacher.org/pubs/tgr/04/2/gr040208.pdf>.

¹³⁴ Ctrs. for Disease Control, Fact Sheet: HIV/AIDS among Asians and Pacific Islanders 3-4 (May 2007), available at <http://www.cdc.gov/hiv/resources/factsheets/API.htm> (last viewed Sept. 11, 2007)

¹³⁵ *Id.* at 3-4; HIV/AIDS among Women, *supra* note 25.

¹³⁶ Marianne Lavelle & Marcia Coyle, *Unequal Protection: The Racial Divide in Environmental Law*, NAT. L. J., Sept. 21, 1992.

¹³⁷ See LUKE W. COLE & SHEILA R. FOSTER, FROM THE GROUND UP: ENVIRONMENTAL RACISM AND THE RISE OF THE ENVIRONMENTAL JUSTICE MOVEMENT 57 (2001).

Twenty years after the UCC report, researchers have concluded that “race continues to be an independent predictor of where hazardous wastes are located, and it is a stronger predictor than income, education and other socioeconomic indicators.”¹³⁸ Using 2000 U.S. Census Bureau data, the update report, *Toxic Wastes and Race at Twenty*, found racial disparities to be greater than in the original 1987 study. People of color now comprise 56 percent of the population living within three kilometers (1.8 miles) of the nation’s 413 commercial hazardous waste facilities. People of color comprise 69 percent of the population living in neighborhoods with clustered hazardous waste facilities. The comprehensive study found that the slow government response to environmental racism unnecessarily jeopardizes the health and welfare of the most vulnerable populations in the United States, and that “having the facts and failing to respond is explicitly discriminatory and tantamount to an immoral ‘human experiment.’”¹³⁹ For instance, although African Americans represent only 12.7 % of the U.S. population, they account for 26 % of asthma deaths,¹⁴⁰ the highest rate of any racial/ethnic group.¹⁴¹ This outcome is predictable and largely the result of African Americans’ homes being close to toxic dumps, toxic fumes and other environment hazards.

(d) The emerging frontier: genetic discrimination and the impact of new technologies

Emerging genetic technologies (genetic, reproductive and biomedical) have the potential to greatly advance scientific and medical knowledge in the treatment of disease. At the same time, these technologies carry social, ethical and legal implications which have the ability to undermined public health initiatives, possibly deepen health disparities and leave people in the United States susceptible to genetic discrimination. The history of genetic discrimination in the United States is unfortunately tied to racial discrimination.

During the 1970s, sickle cell screening programs were developed to identify individuals with sickle cell trait in an effort to reduce the incidence of sickle cell disease. Currently, 1 in 12 African Americans is a carrier for sickle cell anemia.¹⁴² In the past however, this information was used by insurance companies to either deny health insurance coverage to African Americans, or in the alternative, charge higher rates to African Americans who were merely carriers of the gene.¹⁴³ African Americans further suffered discrimination from the Air Force Academy and the airline industry where sickle-cell carrier status was used to exclude African Americans from the academy, flight training, and flight personnel positions.

¹³⁸ BULLARD ET AL., *supra* note 50, at xii.

¹³⁹ *Id.*

¹⁴⁰ AM. LUNG ASS’N , LUNG DISEASE DATA IN CULTURALLY DIVERSE COMMUNITIES: 2005, *available at* <https://www.tpchd.org/files/library/53825cab98d3a28b.pdf>; Am. Lung Ass’n, Lung Disease Data at a Glance: Asthma, <http://www.lungusa.org/site/pp.asp?c=dvLUK9O0E&b=312474> (last visited Nov. 19, 2007).

¹⁴¹ LUNG DISEASE DATA IN CULTURALLY DIVERSE COMMUNITIES, *supra* note 140.

¹⁴² B.B. Robinson, *Addressing the Most Painful Discrimination*, CNSNEWS.COM, <http://www.cnsnews.com/news/viewstory.asp?Page=/Commentary/archive/200706/COM20070619a.html>.

¹⁴³ Kathy L. Hudson et al., *Genetic Discrimination and Health Insurance*, VHL FAMILY FORUM, *available at* <http://www.vhl.org/newsletter/vhl1996/96aqinsu.htm>.

Unfortunately, genetic discrimination amongst racial minorities continues. In 1998 the U.S. 9th Circuit Court of Appeals decided that Lawrence Berkeley National Laboratory in California violated the American Disability Act when they secretly tested African American employees for sickle cell anemia and then conditioned hiring based upon this testing.

The past ten years has seen a dramatic increase in the number of tests available for genetic conditions. Currently there are over 1,000 genetic tests in use. These tests open up the possibility that employers and insurers will use genetic information in a discriminatory matter. Of utmost concern is that in the United States, with no universal health insurance coverage plan, many individuals, particularly those of color, could still be susceptible to discrimination. The Council for Responsible Genetics reports that as many as five hundred cases have been documented where individuals have been barred from employment or lost health and life insurance due to a perceived genetic abnormality.¹⁴⁴ Ironically, the majority of Americans receive their health care through their employer, so if an individual is discriminated against and not hired due to their genetic make-up, it increases the barriers to accessing affordable health care coverage for that person.

Laws addressing genetic discrimination vary by state. The restrictions on the use of genetic information in health insurance address a range of issues, from restricting health insurers from requiring genetic testing of applicants to using genetic information to determine eligibility for a particular health insurance plan. What is most problematic is that the state laws do not govern the use of genetic information in employer-sponsored health benefit plans where more than 59.7 percent of American receives their health care.¹⁴⁵ Overall, 47 states do offer some type of protection from insurance discrimination. Yet this patchwork of legislation sidesteps the issue of whether employers and insurance companies should even have access to genetic information.

At the federal level, laws such as the Americans with Disabilities Act (ADA) and the Health Insurance Portability and Accountability Act (HIPAA) do not explicitly prohibit an employer from requiring employees to take a genetic test as a condition of employment, nor do they deny private insurers from denying insurance to individuals depending upon what one's genetic information may reveal. Current federal legislation, the Genetic Information Non-Discrimination Act (GINA) was passed by the House of Representatives on April 25, 2007, yet still has to be considered by the Senate.

The emerging genetic technology of genetic testing provides a pathway for genetic discrimination that could deepen existing racial health disparities. The United States

¹⁴⁴ Council for Responsible Genetics, Genetic Testing, Discrimination, and Privacy, <http://www.gene-watch.org/programs/privacy.html>.

¹⁴⁵ Steven Reinberg, *Record Number of Americans Lack Health Insurance*, U.S. NEWS & WORLD REP., Aug. 28, 2007, available at <http://health.usnews.com/usnews/health/healthday/070828/record-number-of-americans-lack-health-insurance.htm>.

government must take proactive action by passing legislation such as GINA to ensure this does not happen.

E. The adequacy of the government response to racial health disparities

(1) Health care system responses

The US government must comply with CERD and reform the health care system to remedy racial and ethnic disparities in health. The steps taken by the government to date are clearly inadequate. In its 2007 report, the U.S. asserts that “the U.S. Commission on Civil Rights conducts studies and makes recommendations concerning civil rights issues”¹⁴⁶ but does not mention any steps taken to implement these recommendations, nor any of its responsibilities in the field of health care. Similarly, the U.S. report claims that the federal government is “mov[ing] forward on a number of IOM’s recommendations [in the Institute of Medicine’s 2003 *Unequal Treatment* report],” but includes only vague steps that the Department is taking, primarily targeted at changing individual behaviors in the face of systemic factors which are the driving force behind racial disparities in health and health care.¹⁴⁷ A review of Congressional hearings and legislation reveals that little has been done to remedy the disparities cited in the *Unequal Treatment* report.

Although the U.S. cites programs, such as Healthy People 2010, as evidence of its efforts to eliminate health disparities affecting racial and ethnic minority populations,¹⁴⁸ the results of these initiatives have been mixed, and government action has undermined their efficacy. In the Midcourse Review of Healthy People 2010, for example, the government deleted three key objectives: (1) the expansion of access to clinical preventative services for people of color, (2) increasing the number of local health departments with culturally appropriate and linguistically competent community health promotion and disease preventions programs, and (3) improved data collection.¹⁴⁹ These objectives were included in the original Healthy People 2010 report to help remedy racial and ethnic health disparities.

In addition, the Department of Health and Human Services’ Initiative to Eliminate Racial and Ethnic Disparities in Health, which the U.S. report cites, set the goal of reducing racial and ethnic health status disparities for six chronic health conditions, including diabetes, HIV, and infant mortality. But a 2006 report by the Center for Disease Control shows the U.S. has made little progress in these areas,¹⁵⁰ relying instead on what appears to be a piecemeal remedy for systemic disparities in health and access. This approach is

¹⁴⁶ 2007 U.S. Report, *supra* note 5, at ¶ 284.

¹⁴⁷ *Id.* at ¶ 261.

¹⁴⁸ *Id.* at ¶ 262.

¹⁴⁹ Office of Disease Prevention & Health Promotion, U.S. Dep’t of Health & Human Servs., *Appendix D: Healthy People 2010 Objectives and Subobjectives Dropped at Midcourse Review*, HEALTHY PEOPLE 2010 MIDCOURSE REVIEW, D-1, D-2, D-5, available at <http://www.healthypeople.gov/data/midcourse/pdf/Appendix%20D.pdf>.

¹⁵⁰ HEALTH, UNITED STATES, 2006, *supra* note 9.

reflected in the activity of the individual organizations responsible for executing the Initiative's aims.

For example, the Office of Minority Health (OMH) within the U.S. Department of Health and Human Services is intended to act as the focal point for addressing health disparities on the federal level. However, according to the Office of Management and Budget, OMH has only recently developed an overall plan and indicators to measure progress, despite having been originally established in 1986. OMH has seen its budget repeatedly cut (\$56M for FY 2006 to \$44 for FY2008).¹⁵¹ Recently there have been more positive developments. In June 2007, Congress introduced the Minority Health Improvement and Health Disparity Elimination Act (MHIHDEA), which would strengthen OMH funding. Furthermore, to its credit, OMH has been active in research to strengthen local capacity under the community health worker model. OMH has also announced its intent to fund capacity-building¹⁵² and promote partnerships with minority community health organizations to improve both access and utilization.¹⁵³ Nonetheless, these efforts remain at a nascent stage, and more fundamentally, fail to address systemic causes such as coverage and segregation issues.

Similarly, in the wake of *Alexander v. Sandoval*¹⁵⁴ and the limits it imposed on Title VI “disparate impact” claims, the U.S. DHHS Office of Civil Rights (OCR) represents one of the few alternatives for those plaintiffs who seek to prosecute discrimination but lack the ability to directly prove discriminatory intent. However, over the last decade OCR’s staff and budgets have been cut, and its prominence in this arena has suffered.¹⁵⁵ Independent assessments of OCR have questioned the overall direction of the office; in 2004, the U.S. Commission on Civil Rights reported that the organization lacked a “clear agenda.”¹⁵⁶ Since then, as evidenced by an estimation of OCR’s activity via simple literature searches, it appears that OCR has turned its attention to HIPAA and protected health information as a priority over issues of health disparity. While this issue has great health consequences for some minorities (such as American Indian tribes, due to their unique governmental status¹⁵⁷), broader health disparity issues appear to have fallen by the wayside.

By virtue of Medicare’s prominent position in our health system and its history as a tool of social change, the federal Centers for Medicare and Medicaid Services (CMS) have the

¹⁵¹ Detailed information on HHS-OMH assessment. ExpectMore.gov, Health and Human Services - Office for Civil Rights, <http://www.whitehouse.gov/omb/expectmore/detail/10003523.2005.html>.

¹⁵² *American Indian/Alaska Native Health Disparities Program*, Federal Register Extracts: Health and Human Services Department Documents and Publications (July 6, 2007).

¹⁵³ *Community Partnerships To Eliminate Health Disparities Demonstration Grant Program*, Federal Register Extracts Health and Human Services Department Documents and Publications (June 11, 2007).

¹⁵⁴ 532 U.S. 275 (2001).

¹⁵⁵ Dayna B. Matthew, *Disastrous Disasters: Restoring Civil Rights Protections for Victims of the State in Natural Disasters*, 2 J. Health & Biomed. L. 213 (2006).

¹⁵⁶ U.S. COMM’N ON CIVIL RIGHTS, TEN-YEAR CHECK-UP: HAVE FEDERAL AGENCIES RESPONDED TO CIVIL RIGHTS RECOMMENDATIONS, VOL. IV (2004), available at http://www.eric.ed.gov/ERICDocs/data/ericdocs2sql/content_storage_01/0000019b/80/28/0e/36.pdf.

¹⁵⁷ Starla K. Roels, *HIPAA and Patient Privacy: Tribal Policies as Added Means for Addressing Indian Health Disparities*, 31 AM. INDIAN L. REV. 1 (2006).

potential to pioneer health disparities reduction. CMS can use the existing Medicare infrastructure to directly involve communities in education about health disparities, following the model of its efforts to promote the Medicare Part D plan. Likewise, CMS might require providers to collect data on health disparity, thereby greatly simplifying research efforts,¹⁵⁸ or directly fund research itself. CMS' network of oversight could be used to combat provider bias or oversee quality of care.

To date, however, CMS has done none of these things, and observers have noted that health disparity issues do not appear to be currently of a high priority. None of CMS' Government Performance and Results Act documents over the past half-decade have listed disparity issues as one of its priority goals and in any respect CMS does not appear organized to effectively address those issues. Within CMS, no office of minority health or similarly central organization exists,¹⁵⁹ and consequently there is no budget dedicated to such as office to fund initiatives or involve external organizations.¹⁶⁰

(2) Environmental justice responses

The Periodic Report's discussion of the government's efforts to address environmental justice consists of three short paragraphs (§§ 264-66). The brevity of this section reflects the scant amount of work done by the U.S. government to address environmental justice concerns. Significantly, the lead agency responsible for addressing environmental discrimination, the U.S. Environmental Protection Agency (EPA), has been cited by other federal bodies for its failures to implement various legal mandates on environmental justice and for failing to provide meaningful redress to those who complain of environmental injustices. Moreover, EPA's inaction has led other federal agencies to ignore or analyze away disparate environmental impacts on minority communities. The lack of redress for victims of environmental injustice also exists at the state level, where few states have laws that provide redress for victims of environmental injustice.

(a) The EPA is not implementing Executive Order 12898

Executive Order 12898, adopted in 1994, requires that "each Federal agency shall make achieving environmental justice part of its mission by identifying and addressing, as appropriate, disproportionately high and adverse human health or environmental effects of its programs, policies, and activities on minority populations and low-income populations in the United States and its territories." Ten years later, on March 1, 2004, the Office of the Inspector General of the EPA issued an evaluation report, which concluded that EPA had failed to integrate environmental justice into its daily operations, it had failed to identify low-income and minority populations, and it had failed to establish criteria for defining disproportionate impact. The OIG also found that in

¹⁵⁸ Olga Pierce, *Medicare vs. the race gap*, UPI, Jan. 29, 2007.

¹⁵⁹ Although CMS has an Office of Equal Opportunity and Civil Rights (OEOCR), it exists primarily to address employment opportunity discrimination, while Medicare-related civil rights complaints are referred to the Office of Civil Rights.

¹⁶⁰ Timothy S. Jost, *Racial and Ethnic Disparities in Medicare: What the Department of Health and Human Services and the Centers for Medicare and Medicaid Services Can, and Should, Do*, 9 DEPAUL J. HEALTH CARE L. 667 (2005).

restating its commitment to environmental justice in 2001, EPA failed to place emphasis on low-income and minority communities, which was the intent of the executive order. The OIG found that EPA had failed utterly to articulate a clear vision, a comprehensive plan, or performance measures against which agency accomplishments could be measured.¹⁶¹ The OIG issued a second report in 2006 finding that EPA still had not established criteria or evaluated its programs to determine whether they were creating a disproportionate adverse environmental impact on the nation's low-income and minority populations.¹⁶² EPA's failure to act has directly impacted minority populations within the United States. For example, people of color make up the majority (56%) of those living in nearby neighborhoods of the nation's 413 commercial hazardous waste facilities, and race continues to be an independent predictor of the location of such facilities.¹⁶³

(b) The EPA's Title VI complaint process fails to provide meaningful redress to victims of environmental injustice

Like most federal agencies, EPA's Title VI regulations not only bar recipients of federal funds from engaging in acts of intentional discrimination but also bar recipients from using criteria or methods that have the effect of subjecting individuals to discrimination on the basis of race, color, or national origin.¹⁶⁴ EPA's process for investigating Title VI complaints are set forth in agency regulations¹⁶⁵ and a draft administrative guidance published in the Federal Register on June 27, 2000.¹⁶⁶ While EPA has a framework in place for victims of environmental injustice to seek redress, that framework has not proven effective.

In 2003, the U.S. Commission on Civil Rights (USCCR)¹⁶⁷ issued a report that studied the effectiveness of EPA's Title VI Complaint Program.¹⁶⁸ USCCR compiled statistics on Title VI complaints filed with EPA. Of the 124 complaints filed with EPA by January 1, 2002 only 13 cases (10.5%) were processed by the agency in compliance with the agency's 20 day processing rule, and all 13 cases

¹⁶¹ OFFICE OF THE INSPECTOR GEN., U.S. ENVTL. PROT. AGENCY, EVALUATION REPORT: EPA NEEDS TO CONSISTENTLY IMPLEMENT THE INTENT OF THE EXECUTIVE ORDER ON ENVIRONMENTAL JUSTICE, REPORT NO. 2004-P-00007 (2004), *available at* <http://www.epa.gov/oig/reports/2004/20040301-2004-P-00007.pdf>.

¹⁶² OFFICE OF THE INSPECTOR GEN., U.S. ENVTL. PROT. AGENCY, EVALUATION REPORT: EPA NEEDS TO CONDUCT ENVIRONMENTAL JUSTICE REVIEWS OF ITS PROGRAMS, POLICIES, AND ACTIVITIES, REPORT NO. 2006-P-00034 (2006), *available at* <http://www.epa.gov/oig/reports/2006/20060918-2006-P-00034.pdf>.

¹⁶³ *See* BULLARD ET AL., *supra* note 50.

¹⁶⁴ 40 C.F.R. §§ 7.30, 7.35 (2007).

¹⁶⁵ 40 CFR § 120 (2007).

¹⁶⁶ *See*, Draft Revised Guidance for Investigating Title VI Administrative Complaints Challenging Permits, 65 Fed. Reg. 39650, 39667-86 (proposed June 27, 2000), *available at* http://www.epa.gov/ocr/docs/frn_t6_pub06272000.pdf.

¹⁶⁷ The United States Commission on Civil Rights was established to, *inter alia*, submit reports, findings, and recommendations to the President and Congress on matters relating to discrimination on the basis of race, color, religion, sex, age, disability, or national origin. 42 U.S.C. § 1975a(c) (2007).

¹⁶⁸ U.S. CIVIL RIGHTS COMM'N, NOT IN MY BACKYARD: EXECUTIVE ORDER 12898 AND TITLE VI AS TOLLS FOR ACHIEVING ENVIRONMENTAL JUSTICE (2003), *available at* www.usccr.gov/pubs/envjust/ej0104.pdf [hereinafter USCCR 2003].

were ultimately rejected by the agency for investigation based on failure to meet the agency's regulatory requirements.¹⁶⁹ By June 30, 2003 EPA had received a total of 136 Title VI complaints, of which 75 were rejected, and 26 were dismissed. Only 35 complaints were accepted by the agency for further action.¹⁷⁰ Of 35 complaints acted upon by EPA, only 2 were informally resolved by EPA, another 2 were referred to another agency, and the remaining 31 complaints remained in some stage of EPA review.¹⁷¹ The small number of timely processed complaints coupled with an even smaller number resolved complaints strongly suggests that EPA's administrative process for handling Title VI fails to provide meaningful relief to victims of environmental injustice.

Noting that the U.S. Supreme Court's decision in *Alexander v. Sandoval*¹⁷² gave environmental justice complainants "one less avenue of redress,"¹⁷³ USCCR made a series of recommendations to improve EPA's Title VI Complaint Program. Those recommendations included EPA (and other federal agencies having jurisdiction over environmental justice issues) issuing a final Title VI guidance on processing Title VI complaints and methods to improve permitting programs; conducting independent analyses of adverse disparate impacts in order to determine if they are actually present in a given community; establishing a guideline for its state funding recipients that incorporates an inclusive definition of adverse disparate impact; and conducting Title VI compliance reviews wherein periodically EPA would review the number and type of Title VI complaints and ensure their funding recipients are complying with their Title VI obligations.¹⁷⁴ To date, none of these recommendations have been implemented by the EPA or any other federal agency.

(c) Judicial deference to agencies' consideration of environmental justice impacts fails to insure agencies properly consider disparate impacts

In response to Executive Order 11298, many federal agencies began incorporating an "environmental justice analysis" into Environmental Impact Statements mandated by the National Environmental Policy Act (NEPA). NEPA requires all federal agencies to prepare detailed environmental impact statements ("EIS") for "every recommendation or report on proposals for legislation and other major Federal Actions significantly affecting the quality of the human environment..."¹⁷⁵ The impacts to be considered by federal agencies under NEPA are "ecological (such as the effects on natural resources and on the components, structures, and

¹⁶⁹ *Id.* at 57.

¹⁷⁰ *Id.* at 58.

¹⁷¹ *Id.*

¹⁷² 532 U.S. 275 (2001); see Nat'l Campaign to Restore Civil Rights, *The Lack of Access to Courts and Effective Remedies To Enforce Civil Rights Violations in the United States of America: Violations of Articles 1 and 6 of the Convention on the Elimination of All Forms of Racial Discrimination, Shadow Report in Response to the Second Periodic Report of the United States of America* (2007).

¹⁷³ USCCR 2003, *supra* note 164, at 81.

¹⁷⁴ *Id.* at 77-78.

¹⁷⁵ 42 U.S.C. §4332 (2007).

functioning of affected ecosystems), aesthetic, historic, cultural, economic, social, or health, whether direct, indirect, or cumulative.”¹⁷⁶ However, the agency need only consider economic and social effects to the extent that they are interrelated with the physical environmental effects of an action.¹⁷⁷

As noted above,¹⁷⁸ EPA has failed to establish criteria to determine the existence of disproportionate adverse environmental impact on the nation’s low-income and minority populations. Thus, agencies have developed their own approaches to conducting an environmental justice analysis under NEPA. Frequently, the agency’s analysis of environmental justice impacts fails to properly analyze the disproportionate environmental burdens of proposed federal actions on minority communities. A case in point was the Federal Aviation Administration’s (“FAA”) environmental justice analysis of a proposed runway expansion at Boston’s Logan Airport. The FAA’s environmental justice analysis failed to compare the demographics and environmental impacts on the population of those living in the airport’s immediate vicinity (34% minority) with the population residing in the greater Boston metropolitan area that actually used the airport (85% white.)¹⁷⁹ Instead, the agency compared the population of the immediate area (calling it the “actually affected area”) to that of one county in the Greater Boston area, Suffolk County (calling it the “potentially affected area”), where the minority population was considerably higher (48% minority). The analyses concluded that significant noise impacts would not fall disproportionately on minorities. The City of Boston challenged the FAA’s environmental justice analysis in federal court, claiming that the FAA erred by not comparing the demographics of the population immediately surrounding the airport to that of the airport’s service area. The Court ruled it had jurisdiction to review the FAA’s environmental justice analysis because the agency exercised its discretion to include the analysis in its NEPA evaluation. However, the Court failed to overturn the FAA’s analysis finding that the “FAA’s choice among reasonable analytical methodologies is entitled to deference from this court.”¹⁸⁰

Judicial deference given to environmental justice analyses such as the FAA’s is not surprising given the lack of criteria on how agencies should conduct those analyses. EPA is the federal agency best suited to develop those criteria, but it has failed to do so, in spite of its obligations under Executive Order 12898. Until standards are promulgated, courts will continue to defer to the agency’s choice of methodology, no matter how flawed, so long as an agency can convince a court

¹⁷⁶ 40 C.F.R. §1508.8 (2007).

¹⁷⁷ 40 C.F.R. §1508.14 (2007).

¹⁷⁸ See REPORT NO. 2006-P-00034, *supra* note 158.

¹⁷⁹ According to 2000 census data, whites comprised 85% of the population of the Boston-Worcester-Lawrence-Lowell-Brockton, Mass. Standard Metropolitan Statistical Area (SMSA) (5,147,035 out of a total population of 6,057,826) (derived from Census 2000 Summary File 1 (SF 1) 100-Percent Data on U.S. Census web site, www.census.gov on Nov. 7, 2007).

¹⁸⁰ *Cmtys. Against Runway Expansion, Inc. v. FAA*, 355 F.3d 678, 689 (D.C. Cir. 2004).

that the methodology used in its environmental justice analysis is “reasonable and adequately explained.”¹⁸¹

(d) Victims of environmental injustice lack redress at the state level

Under federal law, every state environmental agency must establish a grievance procedure to resolve complaints alleging discrimination on the basis of race, color or national origin under Title VI of the Civil Rights Act of 1964, including complaints regarding actions that allegedly have discriminatory impacts.¹⁸² However, as of 2004, only four state environmental agencies had adopted formal discrimination complaint procedures (Alabama, Connecticut, Illinois and Louisiana).¹⁸³ The absence of Title VI grievance procedures at the state level deprives environmental justice complainants of another avenue for redress.

California is virtually alone in expressly providing redress for actions by state agencies or recipients of state funds that have the effect of discriminating on the basis of race, color or national origin. California has a state law similar to Title VI that bans discrimination on the basis of race, color, national origin and “ethnic group identification” in “any program or activity that is conducted, operated, or administered by the state or by any state agency, is funded directly by the state, or receives any financial assistance from the state.”¹⁸⁴ Regulations implementing California’s version of Title VI define unlawful discrimination to include actions that “have the purpose or effect of subjecting a person to discrimination . . . ,” including the issuance of permits or selection of sites or location of facilities.¹⁸⁵ Unlike regulations implementing Title VI, regulations implementing California’s version of Title VI can be enforced by private parties in an action seeking injunctive relief.¹⁸⁶

While states generally do not provide legal redress for government actions that impose disproportionate environmental burdens on communities of color, several states have enacted legislation requiring their respective state environmental agencies to take certain actions to promote environmental justice.¹⁸⁷ In Rhode Island, the state’s Department of Environmental Management must consider the effects that contaminated site clean-ups would have on the populations surrounding each site and the issues of environmental

¹⁸¹ *Id.*

¹⁸² “Each recipient shall adopt grievance procedures that assure the prompt and fair resolution of complaints which allege violations of this part [7 of Title 40 of the Code of Federal Regulations]. 40 C.F.R. § 7.90(a) (2007).

¹⁸³ R.I. Legal Servs., *Environmental Justice for States: A Guide for Developing Environmental Justice Programs for State Environmental Justice Agencies*, at 32 (Report to the U.S. Environmental Protection Agency, Grant No. 98197001 2006), available at <http://www.dem.ri.gov/envequity/pdf/rilsrept.pdf> (last accessed Nov. 7, 2007).

¹⁸⁴ CAL. GOV’T CODE §11135(a) (2007).

¹⁸⁵ CAL. CODE REGS. tit. 22 §§98101(i), (j) (2007).

¹⁸⁶ CAL. GOV’T CODE §11139 (2007).

¹⁸⁷ *See* AM. BAR ASS’N ET AL., *ENVIRONMENTAL JUSTICE FOR ALL: A FIFTY STATE SURVEY OF LEGISLATION, POLICIES, AND INITIATIVE* (Steven Bonnorris ed., 2004), available at <http://www.abanet.org/irr/committees/environmental/statestudy.pdf> (last accessed Nov. 7, 2007).

equity for low-income and racial minority populations.¹⁸⁸ Similarly, in Kentucky, the state environmental agency must consider both the social and economic effects of issuing a certificate of environmental safety and public necessity for the siting of a facility.¹⁸⁹ The state of Arkansas enacted a law that prohibits the siting of landfills within twelve miles of each other. More specifically, it states that there is a “rebuttable presumption against permitting the construction or operation of any high impact solid waste management facility within twelve miles of any existing high impact solid waste management facility.”¹⁹⁰ Even though there are exceptions to this presumption, the purpose underlying the statute is to avoid the concentration of solid waste disposal facilities in low-income and minority communities.

F. Recommendations

Both federal and state governments must undertake far reaching structural reforms to comply with the Convention and eliminate racial disparities in health status and medical care. In the U.S., states and the federal government share the responsibility of regulating public health and health care. As a result, both levels of government have an affirmative obligation to fulfill the Convention’s requirements.

(1) Federal Government

Universal health insurance: A universal health care insurance system will greatly reduce financial barriers to effective and equitable distribution of health care resources, because it will equalize incentives for hospitals, health care systems, and private providers to serve a range of communities regardless of their wealth or poverty.

Data collection and analysis: The federal government should ensure that public and private health systems monitor racial and ethnic, gender, language status, immigration status and income-based health care disparities. The federal government must assure that CMS and other federal agencies that finance health care services engage in systematic, periodic analysis of racial disparities in the clinical care programs they support, using standard quality assurance measures.¹⁹¹ The analysis should analyze how certain groups of people experience forms of discrimination differently because they face multiple levels of discrimination on the basis of race, gender, gender identity and sexual orientation, disability, immigration status, etc.

Strengthen and fully implement the 1994 Executive Order: Congress should codify the 1994 Environmental Justice Executive Order (EO 12898) by passing the proposed Environmental Justice Act. The Environmental Protection Agency must also implement

¹⁸⁸ R.I. GEN. LAWS §23-19.14-5 (2006).

¹⁸⁹ KAN. STAT. ANN. §224.46-830 (2006).

¹⁹⁰ ARK. STAT. ANN. § 8-6-1504 (2006).

¹⁹¹ PANEL ON RACIAL & ETHNIC DISPARITIES IN MEDICAL CARE, PHYSICIANS FOR HUMAN RIGHTS, THE RIGHT TO EQUAL TREATMENT: AN ACTION PLAN TO END RACIAL AND ETHNIC DISPARITIES IN CLINICAL DIAGNOSIS AND TREATMENT IN THE UNITED STATES 4 (2003), *available at* <http://physiciansforhumanrights.org/library/report-equaltreatment-2003.html>.

the EPA Office of Inspector General recommendations to EPA on implementing Executive Order 12898.

Cultural competency and language barriers: Health professionals should be trained in cross-cultural medicine to improve provider-patient communication and eliminate pervasive racial and ethnic disparities in the provision of medical care. The federal government should encourage private professionals and administrators to receive training on cultural factors that influence health care, and design care to accommodate those factors.¹⁹² In addition, the government should allocate appropriate resources to health outreach programs that identify and treat vulnerable populations with specific health needs, such as immigrant women who face language and cultural barriers to accessing sexual and reproductive health care. The federal government should also take steps to increase the racial and ethnic diversity of health care providers by reducing or eliminating financial barriers to health professions education for low-income students, strengthen magnet science programs in urban high schools, and, consistent with the U.S. Supreme Court's ruling in the 2004 *Grutter v. Bollinger* decision, support the consideration of applicants' race or ethnicity as one of many relevant factors in higher education admissions decisions.

Federal agency enforcement: The federal government must considerably step up civil rights enforcement in the health care sphere. The Department of Justice can initiate litigation on behalf of an agency, like the U.S. Department of Health and Human Services (HHS), for a violation of Title VI.¹⁹³ And HHS's Office of Civil Rights (OCR) has the power to initiate an investigation of a recipient of federal funds and require the recipient to create a plan to remedy discrimination.¹⁹⁴

Federal agency monitoring: The Department of Health and Human Services' OCR has "hardly developed its Title VI enforcement program since 1980," according to the bipartisan U.S. Commission on Civil Rights.¹⁹⁵ OCR must institute a system of on-site

¹⁹² INST. OF MEDICINE, UNEQUAL TREATMENT 203 (2003).

¹⁹³ See 45 C.F.R. § 80.8 (1) (2006). The Dep't of Justice Guidelines for Title VI Enforcement recognize that "[c]ompliance with the nondiscrimination mandate of title VI may often be obtained more promptly by appropriate court action than by hearings and termination of assistance. Possibilities of judicial enforcement include (1) a suit to obtain specific enforcement of assurances, covenants running with federally provided property, statements or compliance or desegregation plans filed pursuant to agency regulations, (2) a suit to enforce compliance with other titles of the 1964 Act, other Civil Rights Acts, or constitutional or statutory provisions requiring nondiscrimination, and (3) initiation of, or intervention or other participation in, a suit for other relief designed to secure compliance." 28 C.F.R. § 50.3 (2006).

¹⁹⁴ See, e.g., *Caufield v. Bd. of Educ. of the City of New York*, 486 F. Supp. 862 (E.D.N.Y. 1979), *aff'd* 632 F.2d 999 (2d Cir. 1980) (explaining that OCR sent a letter to the Chancellor of the New York City Schools alleging noncompliance with Titles VI and IX in the schools' employment practices and that the Chancellor responded by ordering an internal investigation).

¹⁹⁵ U.S. COMM'N ON CIVIL RIGHTS, TEN-YEAR CHECK-UP: HAVE FEDERAL AGENCIES RESPONDED TO CIVIL RIGHTS RECOMMENDATIONS?, VOL. II, at 77 (2002) [hereinafter TEN-YEAR CHECK-UP, VOL. II]. In 2004, the Commission reported that the Department of Health and Human Services' Office of Civil Rights had failed to improve its compliance reviews since the Commission's 1996 and 1999 evaluations. U.S. COMM'N ON CIVIL RIGHTS, TEN-YEAR CHECK-UP: HAVE FEDERAL AGENCIES RESPONDED TO CIVIL RIGHTS RECOMMENDATIONS, VOL. IV (2004), *available at*

visits or data collection, and collect information regarding “the race, color, or national origin of the population served” and “the location of existing or proposed facilities and information on whether the location will have the effect of denying access to any person on the basis of prohibited discrimination.”¹⁹⁶

Justice Department enforcement: The federal government can also strengthen civil rights agencies’ capacity to investigate racial or ethnic disparities in health through the creation of an Office on Health Disparities in the Civil Rights Division of the Department of Justice (which already has offices dedicated to housing, employment and education).¹⁹⁷

Restore private enforcement: CERD also requires that courts be available to individuals who have suffered from intentional or unintentional discrimination. In *Alexander v. Sandoval* (2001) the U.S. Supreme Court ruled that individuals do not have the right to sue to enforce the Title VI disparate impact regulations, because the statute did not specify a private right of action. Congress should ensure that every statute protecting civil rights specifically authorizes individuals to bring civil suits in federal court to redress violations of the law.¹⁹⁸ Similarly, Congress should clarify the legal right of Medicaid recipients to force state compliance with the Medicaid Act.¹⁹⁹

Health impact assessment: In order to ensure that federal funds for health care are distributed fairly and equitably, HHS should integrate a *Health Impact Assessment* (HIA) tool into the domestic policy agenda to determine the effect that new legislation will have on the health of people of color.²⁰⁰ The impact tool, which includes mechanisms for public participation, could be used by federal, state, and local agencies to ensure that all decisions and programs are evaluated to determine their potential impact on the health status of affected communities.

http://www.eric.ed.gov/ERICDocs/data/ericdocs2sql/content_storage_01/0000019b/80/28/0e/36.pdf [hereinafter TEN-YEAR CHECK-UP, VOL. IV].

¹⁹⁶ TEN-YEAR CHECK-UP, VOL. IV, *supra* 191, at 144-45. The Department of Justice coordination regulations mandate that federal agencies collect sufficient data “to permit effective enforcement of title VI.” *See, e.g.*, 28 C.F.R. § 42.406(a) (2006). The Department of Justice’s coordination regulations describe specific implementation, compliance, and enforcement obligations of federal funding agencies under Title VI. *See* 28 C.F.R. §§ 42.401-42.415 (2006). Every agency that extends federal financial assistance covered by Title VI is subject to the Coordination Regulations and Title VI Guidelines issued by the Department of Justice. *See* CIVIL RIGHTS DIV., U.S. DEP’T OF JUSTICE, TITLE VI LEGAL MANUAL, *available at*

<http://www.usdoj.gov/crt/cor/coord/vimanual.htm#XIII.%20Department%20of%20Justice%20Role%20Under%20Title%20VI>.

¹⁹⁷ PANEL ON RACIAL & ETHNIC DISPARITIES IN MEDICAL CARE, *supra* note 187, at 4.

¹⁹⁸ WILLIAM L. TAYLOR ET AL., CITIZENS’ COMM’N ON CIVIL RIGHTS & CTR. FOR AM. PROGRESS, THE EROSION OF CIVIL RIGHTS: DECLINING CIVIL RIGHTS ENFORCEMENT UNDER THE BUSH ADMINISTRATION 9 (2007).

¹⁹⁹ Jane Perkins, *Health Care: The Civil Rights Rollback: It’s Bad for Your Health*, in AWAKENING FROM THE DREAM, CIVIL RIGHTS UNDER SIEGE AND THE NEW STRUGGLE FOR EQUAL JUSTICE 179 (Denise C. Morgan et al., eds. 2006).

²⁰⁰ Ctrs. for Disease Control, Health Impact Assessments, <http://www.cdc.gov/healthyplaces/hia.htm>.

Hold Congressional hearings on EPA’s response to contamination in minority communities: Given the disproportionately high number of toxic waste sites in minority communities, Congress should hold hearings on EPA’s response to toxic contamination in those communities, such as Post-Katrina New Orleans.

EPA should implement the U.S. Commission on Civil Rights’ recommendations regarding Title VI complaint process: The U.S. Commission on Civil Rights’ recommendations regarding the investigation of environmentally-related civil rights complaints under Title VI of the Civil Rights Act should be implemented. These recommendations include:

- EPA’s (and other federal agencies having jurisdiction over environmental justice issues) issuing a final Title VI guidance on processing Title VI complaints and methods to improve permitting programs;
- EPA’s conducting independent analyses of adverse disparate impacts in order to determine if they are actually present in a given community;
- EPA’s establishing a guideline for its state funding recipients that incorporates an inclusive definition of adverse disparate impact; and
- conducting Title VI compliance reviews where periodically EPA would review the number and type of Title VI complaints and ensure their funding recipients are complying with their Title VI obligations.²⁰¹

EPA should require state-by-state assessments (report cards) on environmental justice and require states to adopt Title VI grievance procedures: From 1993 to the present, nearly three dozen states have expressly addressed environmental justice.²⁰² However, little is known about the efficacy of these laws and whether these laws are being enforced. EPA should require all state environmental agencies to evaluate and report on their progress made on environmental justice. Moreover, EPA should require state environmental agencies to adopt Title VI grievance procedures as required by EPA’s Title VI regulations.²⁰³

(2) State Governments

Data collection: State Departments of Health should collect data and monitor disparities in health care access and quality on the basis of income, race, ethnicity, gender, gender identity and sexual orientation, primary language, and immigration status. As the U.S. Commission on Civil Rights emphasized in its 2002 report, states must establish “quality assurance measures to ensure that minorities and women benefit equally from state recipients’ programs.”²⁰⁴ State agencies are already required to implement a Title VI compliance program, including data collection and record maintenance, to ensure that both Departments of Health and the facilities to which Departments of Health convey

²⁰¹ USCCR 2003, *supra* note 164, at 77-78.

²⁰² BULLARD ET AL., *supra* note 60, at xiv.

²⁰³ 40 C.F.R. § 7.90(a) (2007).

²⁰⁴ U.S. COMM’N ON CIVIL RIGHTS, THE HEALTH CARE CHALLENGE: ACKNOWLEDGING DISPARITY, CONFRONTING HEALTH DISCRIMINATION AND ENSURING EQUALITY, VOL. I, at 20 (1999).

federal assistance meet the nondiscrimination requirements of Title VI of the Civil Rights Act of 1964.²⁰⁵ Collection of this information provides the foundation for addressing disparities in access to health care.²⁰⁶

Certificate of Need: States must ensure that their Departments of Health consider the public's health needs in decisions affecting hospitals and clinics. Obtaining a Certificate of Need (CON) – the regulatory prerequisite for service changes in many states – should be contingent on evidence that the changes sought would reduce racial and economic health care inequality.²⁰⁷ Historically, the purpose of the Certificate of Need process has been to control health care costs and ensure that capital and technology investments in the health care industry reflect community needs. In most states that employ CON, the process has required hospitals or other health care institutions that seek to establish or expand services to submit proposals so that state boards can evaluate projects to eliminate unnecessary duplication of services and ensure that investments strategically address health care needs. But the process has met significant resistance and criticism for its failure as a cost-containment measure. The CON process, however, has great potential to encourage a better distribution of health care resources, reflect community and statewide need. States should re-evaluate, and in some cases reinvigorate CON through new policies that ensure accountability for the use of public funds.

Community health planning: Community health planning seeks to strengthen communities by actively involving residents in the planning, evaluation, and implementation of the health care and public health programs in their communities. The 1974 National Health Planning Law sought to create and support a network of state health systems agencies, but federal funding was cut from the program, and most states' have halted their health planning efforts. States must examine strategies to reinvigorate local health planning agencies. Without health planning, market forces often dictate the distribution of resources, leaving low-income communities of color without adequate quality health care. States should consider reinstating and funding community-based health planning and should include health disparities reduction efforts as part of the mission of these planning agencies.

Cultural competency and a diverse health care work force: Most states are experiencing rapid growth in the population of racial and ethnic minority and language-minority residents. Already, four states and the District of Columbia are “majority minority,” and nearly one in two U.S. residents will be a person of color by mid-century. These demographic changes require that the health professions keep pace by training future and current providers to manage diversity in their practice. Some states have taken

²⁰⁵ 28 C.F.R. § 42.410 (2006) (DOJ Coordination regulations).

²⁰⁶ See generally Vernellia R. Randall, *Eliminating Racial Discrimination In Health Care: A Call For State Health Care Anti-Discrimination Law*, 10 DEPAUL JOURNAL OF HEALTH CARE LAW 1 (Fall 2006)

²⁰⁷ David B. Smith, *Eliminating Disparities in Treatment and the Struggle to End Segregation* 17 (Commonwealth Fund, Commonwealth Fund Publication No. 775, 2005), available at http://www.cmf.org/usr_doc/775_Smith_ending_disparities_in_treatment.pdf (noting that “[c]urrently, specialized services such as open-heart surgery are moving from the inner suburbs of most urban areas to the outer ones, following white flight and urban sprawl. Market and convenience justifications mask a resegregation of care that increases the cost of health care and reduces its quality.”).

action to address this need—as of 2005, New Jersey required that all physicians practicing in the state must attain minimal cultural competency training as a condition of licensure. Other states should follow suit. States must work to increase the racial and ethnic diversity of the health care workforce. Studies, including a 2004 Commonwealth Fund report, demonstrate that racial and ethnic minority health care providers are more likely to work in minority and medically underserved communities, and that patients of color are more likely to be satisfied with care provided by a diverse group of professionals.²⁰⁸ Furthermore, increased diversity at the top levels of hospital administration can have a positive impact on the care provided, including more culturally and linguistically appropriate services.²⁰⁹

Investment in underserved communities: Low-income and minority communities often have the most pressing need for health care services, but they are served by a dwindling number of providers and institutions that lack resources to expand and improve services. States have attempted to address this imbalance by providing incentives, such as funds for graduate medical education programs that focus on underserved populations, tuition reimbursement and loan forgiveness programs that require service in health professional shortage areas, and they should continue providing such incentives. In addition, states should support “safety net” hospitals and reduce the financial vulnerability of health care institutions serving poor and minority communities. These “safety net” institutions may fare better in states where near-universal health insurance coverage proposals are enacted and where health insurance expansions are realized, but they will likely continue to face financial vulnerability until universal coverage is achieved.²¹⁰

²⁰⁸ Lisa A. Cooper & Neil R. Powe, Disparities in Patient Experiences, Health Care Processes, and Outcomes: The Role of Patient-Provider Racial, Ethnic, and Language Concordance (Commonwealth Fund, Commonwealth Fund Publication No. 753, July 2004), *available at* http://www.cmwf.org/usr_doc/Cooper_disparities_in_patient_experiences_753.pdf.

²⁰⁹ ANNETTE FUENTES, PRLDEF, CONDITION CRITICAL: THE ABSENCE OF LATINOS AMONG POLICYMAKERS IN NEW YORK CITY’S VOLUNTARY HOSPITALS 3, 8-9 (2004), at http://www.prldef.org/Archives_Webpages/Policy/PDF/Condition_Critical.pdf.

²¹⁰ INST. OF MEDICINE, UNEQUAL TREATMENT (2003).