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### **RACIAL HEALTH DISPARITIES AND DISCRIMINATION<sup>1</sup>**

#### **Submitted by:**

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#### **Endorsed by the Following 31 Organizations and 57 Individuals:**

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<sup>1</sup> This document is based on “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 , Submitted by the CERD Working Group on Health and Environmental Health, A Report to the U.N. Committee on the Elimination of Racial Discrimination (January 2008)”. See also, Vernellia Randall, *Dying While Black* (2006).

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<sup>2</sup> Organization for Identification Purposes Only

The United States signed the Universal Declaration of Human Rights (UDHR or the Declaration), adopted by the United Nation on December 10, 1948. Under the Declaration of Human Rights, the U.S. is obligated to strive to secure effective recognition and observance of the substantive rights enumerated in the Declaration. Article 25 pertains to the right of an individual to a “standard of living adequate for the health and well-being of himself and of his family. . . .” That well-being specifically includes “special care and assistance” for mothers and children.

1. The U.S. ratified the International Convention on the Elimination of All Forms of Racial Discrimination (CERD) on October 21, 1994. Under CERD, Article 5, the U.S. is obligated to “undertake to . . . eliminate racial discrimination in all its forms and to guarantee the right of everyone to equality before the law. . . , [including] the right to public health, medical care, social security and social services.”
2. This report will focus on the United States’ compliance with its obligations to eliminate discrimination on the basis of race and ethnicity in securing health-related rights. Other reports submitted to the Universal Periodic Review examine non-compliance by the U.S. with obligations to secure other health-related rights pursuant to the human rights instruments to which the United States is a party.

### **CURRENT NORMATIVE AND INSTITUTIONAL FRAMEWORK FOR THE PROMOTION AND PROTECTION OF HUMAN RIGHTS RELATED TO RACIAL HEALTH DISPARITIES**

3. The United States federal and state governments must undertake far-reaching structural reforms to comply with the International Convention on the Elimination of All Forms of Racial Discrimination (CERD) and eliminate racial disparities in health and health care.
4. The United States lacks a national coordinated infrastructure for the promotion and protection of human rights. Moreover, mechanisms for remedial action vary from state to state, and the United States has over the last decade retreated on its obligation to guarantee effective remedies to discrimination on the basis of race and ethnicity in the health area.
5. The United States has an obligation not to sponsor, defend or support discrimination – at any level of government -- and to review governmental policies and change laws “which have the effect” of perpetuating discrimination. (CERD Art. 2 (1)(a)-(c).) By contrast, in the United States, though the government not only regulates but pays for the majority of the health care dollar, it privatizes choices including where services are located and which patient populations providers choose to serve with no comprehensive system to monitor whether these choices are discriminatory. Government insurance programs such as Medicare and Medicaid account for just under half of health care expenditures in the US, with more government money flowing through tax subsidies and targeted programs. Despite an even greater government role in some sectors, such as the nursing home industry, these sectors engage in exclusionary and racially segregatory practices. Despite these apparent human rights violations, there is no comprehensive data collection, only skeletal enforcement, and no ability for individuals who have been discriminated against to go to court to challenge unjustified governmental actions with a disparate impact on the basis of race or ethnicity outside of a few local jurisdictions.

### **INFORMATION ON THE IMPLEMENTATION OF INTERNATIONAL HUMAN RIGHTS OBLIGATIONS RELATED TO ELIMINATING RACIAL DISPARITIES IN HEALTH**

6. Article 5 of CERD provides that “States Parties undertake to prohibit and to eliminate racial discrimination in all its forms” in 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 factors affecting health.
7. Structural deficiencies in the U.S. health care system adversely affect all people, especially lower income people, regardless of race or ethnicity. However, people of color face additional health burdens and inequities. Racial and ethnic disparities in health outcomes in the U.S. are caused not only by structural inequities in our health care system, but also by a wide range of social and environmental determinants of health. Both the Declaration of Human Rights and CERD recognize and encompass this dual analysis.
8. To understand whether the United States is meeting its treaty obligations, it is essential to understand the extent to which racial and ethnic groups experience health disparities. Numerous health disparities among racial and ethnic groups continue to exist in the U.S. These health and health care disparities need to be carefully exposed so that action can be taken to eliminate them.
9. African Americans live 6-10 fewer years than White Americans, and face higher rates of illness and mortality. Had mortality rates of African Americans been equivalent to that of whites between 1991 and 2000, over 880,000 deaths would have been prevented. Racial and ethnic gaps persist across a range of health conditions. For instance, the prevalence of diabetes amongst American Indians and Alaska Natives is more than twice that for all adults in the U.S. The age-adjusted death rate for cancer among African Americans was approximately 25% higher than for White Americans in 2001. African Americans, American Indians, and Pacific Islanders experience a disproportionate burden of poor health in problems ranging from infant mortality and diabetes to cardiac disease, HIV/AIDS, and other illnesses. And while some racial /ethnic groups – such as Hispanics and Asian Americans – have better overall health status than some other racial/ethnic minority groups, they still suffer disproportionately from chronic diseases such as diabetes, and tend to experience poorer health outcomes the longer they and their descendants live in the U.S.
10. The health status of subpopulations within racial groups varies considerably on the basis of nationality, immigration status, and other factors.
11. As mentioned, the Declaration of Human Rights specifically includes (Article 25) rights including “special care and assistance” for mothers and children. Nevertheless, there are disparities in the U.S. in relation to women’s health. In every aspect of reproductive health, women of color in the U.S. fare significantly worse than White women. There are substantial disparities in rates of unintended pregnancy, which reflects problems in access to contraception as well as the lack of comprehensive, medically accurate sex education. .
12. Studies by the CDC show that disproportionate rates of HIV & STIs among minority women are high not because of risky individual behavior but because of long standing, unaddressed structural inequalities affecting communities: unstable housing, limited social mobility, high rates of incarceration, all factors making economic independence difficult to obtain thereby leaving minority women vulnerable to abusive, unstable, or asymmetrical relationships in which safer-sex negotiation is difficult to impossible.
13. Although infant mortality decreased among all races between 1980 and 2000, the Black-White gap in infant mortality widened. Racial and ethnic group differences persist even when socioeconomic factors are considered. In fact, despite their high socioeconomic status, African American women with college or graduate degrees have infant mortality rates that are higher than those among White women with less than a high school education.

14. The United States has failed to meet its treaty obligation under CERD Article 5 to “undertake to . . . eliminate racial discrimination in all its forms and to guarantee the right of everyone to equality before the law. . . , [including] the right to public health, medical care, social security and social services.” It has failed to address (1) historical and current racial bias, racial prejudice and discrimination; (2) racial disparities in social and environmental determinants of health; and (3) racial disparities in health care system access and treatment.

### **The Health Effects of Racial Bias, Prejudice and Discrimination**

15. There is increasing evidence that race-based discrimination is not only emotionally harmful, but physiologically damaging to minority Americans. A growing body of research, using innovative methods, is beginning to uncover the toll that such discrimination is taking. Researchers found that everyday discrimination was associated with a variety of health conditions, such as chronic cardiovascular, respiratory, and pain-related health issues.
16. Race-related discrimination undermines health in several ways. From a developmental perspective, the influence of negative environments associated with structural racism and residential segregation has a profound and debilitating effect on health and development of young children. Intergenerational and life-span effects of race discrimination suggest that the health effects of racism carry forward over time in individuals and across generations.

### **Recommendations: Reducing Bias, Prejudice and Discrimination**

17. The federal government should strengthen civil rights agencies’ capacity to investigate racial or ethnic disparities in health and health care 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) and/or in OCR. These special units should be charged with focusing on racial and ethnic disparities in access to care and quality of treatment including assess data on disparities in quality of care.
18. The federal government must intensify its civil rights enforcement not only in health care but all areas. The Department of Justice should initiate litigation on behalf of an agency for a violation of Title VI. The Offices of Civil Rights (OCRs) in the various federal agencies, including but not limited to the Department of Health and Human Services should investigate a recipient of federal funds and require the recipient to create a plan to remedy racial discrimination.
19. Each state should provide to the federal government complete information on the racial and ethnic groups within its borders. Data must the include the multiple forms of discrimination faced by certain ethnic or racial groups, including non-citizens and indigenous peoples. Finally, in recognition of the fact that “certain forms of racial discrimination may be directed towards women specifically because of their gender” or may “have a unique and specific impact on women,” states should address the intersection between race and gender.

### **Racial Disparities in Social Determinants of Health**

20. The neighborhood and community contexts in which people live powerfully shape health risks, access to health care resources, and their health behaviors. Many people of color live in racially segregated neighborhoods, 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.

21. Residential segregation harms the health of people of color in multiple ways. Segregation concentrates non-Whites in areas with limited financial and human resources, and such neighborhoods are home to poor public education, inadequate food sources, inadequate health care, toxic living conditions, inferior housing and public spaces, higher rates of disorder and crime, and a dysfunctional criminal justice system and higher incarceration rates. 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.
22. To the extent that segregated neighborhoods suffer from poor schools, poor access to jobs and employment, inadequate public services such as transportation, and a lack of economic investment – all problems that disproportionately burden communities of color – the opportunity for individuals to advance economically, and therefore improve health status, is constrained.

### **Recommendations: Eliminating Racial Disparities in Social Determinants of Health**

23. The federal government should integrate a *Health Impact Assessment* (HIA) tool into the domestic policy agenda to determine the effect of all new legislation and policy changes on the health of people of color. 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.
24. The White House should convene an *Interagency Task Force* to examine systemic practices that underlie the structure and operation of not only the modern health care system but also other social determinants of health, particularly residential segregation, economic well-being, education, and criminal justice. This task force should also address the underlying structures that foster racism, including prejudice, stereotyping, and cultural ignorance.
25. The federal and state governments should convene local and/or municipal fact-finding inquiries to which private-and public-sector employees can present testimony on current intentional and/or disparate impact discrimination in area workplaces. Such testimonies will document workplace violations of CERD and inform federal and state recommendations.
26. In order to ensure that federal funds are distributed fairly and equitably, federal agencies, like the Department of Health and Human Services (HHS), should require recipients of funding, like state health departments, to review how a potential policy, such as a hospital opening or closing, will impact racial and ethnic communities *before*, rather than after, programs are finalized and implemented. Federal agencies should require a disparate impact analysis as a substantive compliance condition, as opposed to a post-complaint enforcement response.
27. Minority communities often have the most pressing need for health care services, educational services, and housing, but they are served by a dwindling number of providers and institutions that lack resources to expand and improve services. This overall complex of disparities is largely attributable to the predatory practices of banks and other financing organizations, which has been shown to severely undermine the economic infrastructure of minority and other communities. Proper federal regulation of these federally insured businesses is a necessary first step in restoring balance to the communities.

### **Racial Disparities in Health System Access and Quality of Care**

28. Communities of color continue to experience significant disparities relative to Whites in both access to care and in the quality of care received. 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.

29. Causal factors include the policies and practices of health care systems, the legal and regulatory context in which they operate, and the behavior of people who work in them, lack of adequate insurance coverage, separate and unequal care for low-income and minority patients, inequitable distribution of health care resources, lack of a regular source of health care, language barriers, and the actual clinical encounter with the health care provider.
30. Discriminatory treatment of immigrants is pervasive. Immigrants and others for whom English is not their native language face linguistic barriers in accessing care at facilities, the offices of practitioners, pharmacies and mental health providers. American hospitals are now engaging in what has been called medical deportation – the private repatriation of seriously injured or ill immigrants when hospitals cannot find nursing homes or other care providers who are willing to take patients without insurance. American immigration authorities have played no role in these repatriations despite American law, which rests jurisdiction for issues of immigration and deportation exclusively to federal authority.

### **Recommendations: Racial Disparities in Health System Access and Quality of Care**

31. The high percentage of uninsured and underinsured people of color makes it clear that the U.S. must establish a universal health system, Medicare-for-all, that provides high-quality care that is available, accessible and acceptable to all Americans, regardless of race, gender, ethnicity, immigration status, sexual orientation, disability or ability to pay. Such a 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. It will also foster a better integration of public health with medical care, and encourage other intersectoral approaches that can address the social determinants of health. The current health care reform falls far short of this .
32. The US should take concrete steps to address persistent disparities in access to health care and the quality of health provided in areas of longstanding concern, including maternal and child health, reproductive and sexual health, health care access for immigrants, and the quality of health care available for young people in juvenile detention and for prisoners.
33. The federal government must assess how policies to expand access (i.e. affordability standards and individual mandates to purchase insurance) or improve quality may differentially affect communities of color, immigrants, and low-income populations.
34. The federal government should integrate a *Health Impact Assessment* tool, described above, to evaluate health care policy. Moreover, in order to ensure that federal funds are distributed fairly and equitably, the Department of Health and Human Services (HHS) should require recipients of funding, like state health departments, to review how a potential policy, such as a hospital opening or closing, will impact racial and ethnic communities *before*, rather than after, programs are finalized and implemented. Federal agencies should require a disparate impact analysis as a substantive compliance condition, as opposed to a post-complaint enforcement response.
35. The state governments have it in their power to develop systems of universal coverage. Some states are ensuring that the coverage system addresses equity concerns, by expanding data collection and taking other steps to end health disparities. All states should adopt good practice measures to reduce racial disparities and consider expanding insurance coverage to all residents.

36. The federal government should ensure that public and private health systems monitor racial and ethnic disparities, language and cultural competencies, and income-based health care disparities. The federal government must assure that the Centers of Medicaid and Medicare 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. Data collection must be as inclusive as possible; it must reflect the diversity of the U.S. population and include immigrant communities with a special recognition of their unique status, including cultural differences, special health needs, and financial concerns. The federal government should mandate states to follow a uniform process in their data collection that includes information on each patient's race, ethnicity and primary language.
37. Licensing standards for health care institutions like hospitals, clinics, community health centers, health insurance plans, and physician offices should require data collection on race and ethnicity which can then be linked to health care utilization and health care outcomes in order to monitor and eliminate health care disparities.
38. Accreditation standards should be established for hospitals, community health centers, and health insurance plans to hold them accountable for meeting performance measures like Cultural and Linguistically Appropriate Services (CLAS) standards to ensure that all patients regardless of race and ethnicity have an equal opportunity to benefit from covered services.
39. As the US federal government has introduced cultural and linguistic standards in its publication, *National Standards for Culturally and Linguistically Appropriate Services in Health Care*, more work has to be done to determine to what extent is it being followed and what impact has it had since its introduction in 2001.
40. The state departments of health should collect data and monitor disparities in access to and quality of health care on the basis of income, race, ethnicity, gender, primary language, and immigration status. 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 federal assistance meet the nondiscrimination requirements of Title VI of the Civil Rights Act of 1964. This information is the foundation for addressing disparities in access to health care.
41. Health professionals should be trained in cross-cultural health care to improve provider-patient communication and eliminate pervasive racial and ethnic disparities in medical care. The federal government should require private professionals and administrators who receive federal funding for their education or who are paid for services via federal programs to receive training on cultural factors that influence health care, and design care to accommodate those factors. HHS must initiate a campaign to ensure that information is made publicly available concerning rights to equal access to quality healthcare. The OCR must develop easy-to-understand guidelines, in multiple languages, for people (particularly immigrants) who use health care facilities on their rights, responsibilities and entitlement to care. OCR should also work with community organizations, advocacy groups and relocation sponsors to disseminate these guidelines and information.
42. The federal and state governments should increase the racial and ethnic diversity of health care providers by reducing or eliminating financial barriers to education and training in the health professions for low-income students, strengthen magnet science programs in urban high schools, and, consistent with the U.S. Supreme Court's 2004 ruling in *Grutter v. Bollinger*, support the consideration of applicants' race or ethnicity as one of many relevant factors in higher education admissions decisions.



43. The state governments have attempted to address the workforce 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. 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. The federal government should financially support safety net public hospitals in underserved, inner-city areas and prevent further closures of public hospitals.
44. The state governments 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 inequality of health care. The CON process, however, has great potential to encourage a better distribution of health care resources, and to 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.
45. The state governments 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.
46. The federal government should provide additional funding for community health centers, which serve a disproportionate number of racial minorities in underserved areas in a cost-effective way.
47. The federal government should review and revise its requirements for citizenship documentation, which have been shown to exclude primarily eligible Hispanics/Latinos from Medicaid benefits.
48. The federal government should reform Medicaid by expanding Medicaid and removing eligibility categories. Low reimbursement rates under state Medicaid programs are a major problem that leads to both inadequate and unequal health care services. When reimbursement rates are too low, health care providers have little incentive to serve individual Medicaid patients or whole communities that desperately need care. States should review and increase Medicaid reimbursement rates for crucial primary, prenatal, and maternal health care services.
49. Congress should clarify the legal right of Medicaid recipients to force state compliance with the Medicaid Act. The judicial system is an important recourse for Medicaid recipients who face barriers to care. Recent court cases, however, have “jeopardiz[ed] the ability of Medicaid beneficiaries to go to court.”

### **Failure to Provide Effective Legal Remedies**

50. The U.S. lacks a national coordinated infrastructure for the promotion and protection of human rights in the health care area. The mission, activities and enforcement powers of the U.S. Commission on Civil Rights are limited and the Commission does not serve this function. It has occasionally issued reports on health-related concerns and refers the complaints that it receives to the appropriate federal, state, or local agency or private organization for action.
51. Though health is the sector of the American economy with the greatest government involvement and accounts for 16% of GDP, there is no regulatory system outside of the loose and bare construct envisioned by Title VI of the Civil Rights Act of 1964 to ensure that the dollars do not perpetuate discriminatory and segregatory patterns. There is no comprehensive data collection,

no periodic and systematic review of data, no agency established with the capacity and mission comparable to the function, and, since 2001, no private right of action to enforce human rights protections.

52. Since 2001, private individuals can no longer go to domestic courts or tribunals to challenge actions with unjustified disparate impacts on the basis of race or ethnicity, even when the actions are taken by local or state government or by private actors receiving governmental money.<sup>3</sup> Title VI of the Civil Rights Act of 1964 promised to aid in this country's efforts to eliminate racial discrimination; it prohibits, "on the ground of race, color, or national origin, [that any person] be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance." However, despite the enactment of Title VI, subsequent judicial interpretation of the Equal Protection Clause and Title VI has significantly limited the ability of citizens and the Executive Branch of government to eliminate racial discrimination in the U.S. Currently, proof of discriminatory animus (intent) is required to bring a discrimination claim in court under the Title VI statute. Citizens are no longer permitted to enforce its implementing regulations, which until 2001 permitted court challenges to government policies with a discriminatory impact. This limitation prevents the U.S. from meeting its treaty obligation to prohibit not only racially discriminatory intent but also racially discriminatory impact in governmental action, government-supported programs, and government policies. This significant limitation on the enforceability of Title VI and its implementing regulations has contributed to the perpetuation and increase of serious racial health disparities.
53. Neither the health care reform bill signed into law "The Patient Protection and Affordable Care Act" nor the proposed reconciliation bill adequately address the problem of racial discrimination in medical treatment. Racial discrimination in medical treatment is a significant problem. The problem with "The Patient Protection and Affordable Care Act of 2010" is that it relied on Title VI of the Civil Rights Act of 1964, without correcting any of the known problems, particularly the courts' interpretation that Title VI only addresses intentional discrimination and that individuals do not have a private right of action for disparate impact discrimination..

### **Recommendations: Providing Effective Legal Remedies**

54. Congress should enact effective anti-discrimination law which defines the coverage to include all health care providers, insurers and third-party payors; defines prohibited discrimination to include both intentional and disparate impact; exempts special measures designed to eliminate health disparities or health care discrimination; define "an Aggrieved Person" broadly to include organization; provide a private right of action on statute and regulations; and, impose Adequate Fines and Regulatory Enforcement.
55. OCRs must increase its enforcement efforts to identify and penalize violations of laws that prohibit discrimination on the basis of race and ethnicity, such as Title VI of the Civil Rights Act of 1964 and the Hill-Burton Act community service obligation. The federal government must increase the capacity of OCR at HHS, provide it with the necessary staff and resources, and encourage it to correct disparities in the quality of health care in the United States.
56. 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) and/or in OCR. These special units should be charged with focusing

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<sup>3</sup> See *Alexander v. Sandoval*, 532 U.S. 275 (2001).

on racial and ethnic disparities in quality of clinical treatment and should assess data on disparities in quality of care.

57. While strict government enforcement of civil rights laws is necessary to ensure compliance, the treaty obligations also requires courts to be available to individuals who have suffered from either intentional or structural discrimination. In *Alexander v. Sandoval*, 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 such violations of the law. Indeed, since the presence and impact of discrimination in the health sphere are so pervasive, Congress should provide in such statutes for “private attorneys general” to bring suits in situations where the actual, measurable impact on those individuals is minimal.
58. States should encourage their Attorney General’s Offices to challenge systemic racial inequities. Attorneys General possess broad authority under *parens patrie* standing, which provides states with the ability to sue to protect the health of their residents. States should also encourage their human rights and civil rights commissions to initiate investigations, file complaints, and conduct studies to prevent and eliminate discrimination. All of these actions are consistent with the state’s “police power” to maintain good order.
59. Congress should clarify the legal right of Medicaid recipients to force state compliance with provisions of the Medicaid Act that are intended to ensure the accessibility and availability of care to individuals with this form of public insurance. The judicial system has historically been an important recourse for Medicaid recipients who face barriers to care. The U.S. Supreme Court ruling in *Gonzaga v. Doe*, 536 U.S. 273 (2002), coupled with the lower court decisions applying the Supreme Court’s holding to the enforceability of provisions of the Medicaid Act, however, have “jeopardiz[ed] the ability of medical beneficiaries to go to court.