RACISM and PUBLIC POLICY

Durban, South Africa
3 - 5 September 2001

CONFERENCE PAPER

Race, Health Care and the Law

Regulating Racial Discrimination in Health Care

Vernellia R. Randall

UNRISD
United Nations
Research Institute
for Social Development

The **United Nations Research Institute for Social Development** (**UNRISD**) is an autonomous agency engaging in multidisciplinary research on the social dimensions of contemporary problems affecting development. Its work is guided by the conviction that, for effective development policies to be formulated, an understanding of the social and political context is crucial. The Institute attempts to provide governments, development agencies, grassroots organizations and scholars with a better understanding of how development policies and processes of economic, social and environmental change affect different social groups. Working through an extensive network of national research centres, UNRISD aims to promote original research and strengthen research capacity in developing countries.

Current research programmes include: Civil Society and Social Movements; Democracy, Governance and Human Rights; Identities, Conflict and Cohesion; Social Policy and Development; and Technology, Business and Society.

A list of the Institute's free and priced publications can be obtained by contacting the Reference Centre.

UNRISD work for the Racism and Public Policy Conference is being carried out with the support of the United Nations Department of Economic and Social Affairs. UNRISD also thanks the governments of Denmark, Finland, Mexico, the Netherlands, Norway, Sweden, Switzerland and the United Kingdom for their core funding.

UNRISD, Palais des Nations
1211 Geneva 10, Switzerland

Tel: (41 22) 9173020
Fax: (41 22) 9170650
E-mail: info@unrisd.org
Web: http://www.unrisd.org

Race, Health Care and the Law:
Regulating Racial Discrimination in Health Care

Vernellia R. Randall

Paper prepared for the United Nations Research Institute for Social Development (UNRISD)
Conference on *Racism and Public Policy*, September 2001, Durban, South Africa

---

Even though socially constructed, race, like geopolitical constructions, conveys both privilege and deprivation. We live in a world marked by poverty and underdevelopment. Eighty percent of the world's population live in countries that have access to less than twenty percent of the world's resources; while the other twenty percent live in the luxury of more than eighty percent of these resources. Similar disparities in resource distribution occurs within countries. Slavery, colonization, neo-colonialism, cultural imperialism and exploitation of the resources of the developing world (predominantly non-white) has resulted in the wealth of the developed world (predominantly white). Even within societies the distribution of valuable resources tracks race, with one group being privileged and the other groups deprived.

That is why this paper refers to “racially privileged” and “racially disadvantaged” groups and countries. I use these terms to highlight the point that both countries and peoples are privileged and disadvantaged based on race. In addition, the question of which group is privileged or disadvantaged will vary from country to country; and the groups that are disadvantaged are not necessarily the numerical minority. Finally, I do not at all intend to assert or imply that there is any biological explanation for the privilege or disadvantage. All privilege or disadvantage related to race is socially constructed from a past and present built on slavery, colonization, neo-colonialism, cultural imperialism and/or racism (both individual and institutional).

The World Health Organization defines health as ". . . a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity."[45] However, for “racially disadvantaged” groups that definition has little validity. Colonialization, slavery, neo-colonialism and racism has assured that the developing world lags behind the developed world and that “racially disadvantaged” groups lag behind “racially privileged” groups.[11] The problem of racism and racial discrimination is evident not only in health status, but also in health care and in health care research. The pervasive nature of racism affects individuals at all economic levels, thus, there cannot be "complete . . . mental and social well-being"[57,45] for “racially disadvantaged” groups until the problem of racism is addressed and resolved.

The first part of this paper will review data on racial disparities in health status in countries afflicted by racial divisions. The second part will discuss racial discrimination in health care, paying special focus on the United States where the issue of discrimination has been systematically studied by public health analysts. Part three will examine racialized conduct in health care research highlighting a few case studies: the Tuskegee syphilis study, the maternal-fetal HIV transmission prevention trials, and bioethics/legal principle of informed consent. Part four will discuss the legal reponses to racial discrimination in health care and health research. And part five will conclude the study by calling on governments to to take a pro-active role in uncovering and dealing with institutionalized racism, and by emphasizing the need for routine and systematic collection of health status and health care data that is disaggregated according to race, gender and socioeconomic positions.

Racial Disparity in Health Status

Equal access to quality health care is a crucial issue facing “racially disadvantaged” groups. The need to focus specific attention on the racism inherent in the institutions and structures of health care is overwhelming. “racially disadvantaged” groups are sicker and dying at significantly higher rates than the majority populations of their countries. Furthermore, people in developing countries are sicker than people in developed countries and these disparities tracks racial lines.

There are many examples of disparities in health status between racial/ethnic groups. In the United Kingdom, Black people tend to have a greater incidence of high blood pressure than white people.[68] In Brazil, the infant mortality rate for children under 12 months is 62.3 per 1000 for Black and Brown children compared to 37.3 for White.[69] The life expectancy in the United States is 26 years longer than life expectancy in Haiti .[70] In Australia, life expectancy at birth is 56.9 years for Indigenous men and 61.7 years for Indigenous women, compared with 75.2 years and 81.1 years, respectively, for non-Indigenous men and women.[71] The American Indian death rate from diabetes is 27.8 per 100,000, compared with 7.3 for Whites--380 percent higher.[45] In the United States, Black women are three times more likely to die while pregnant than White women, and four times more likely to die in childbirth. The maternal mortality rate for Hispanic women is 23 percent higher than for non-Hispanic women. Disparity occurs at all income-level.[45] The mortality stratum for all of African is either high or very high Child /Adult, while all of Europe is either low or very low child and most of Europe is low or very low adult. Only Estonia, Hungary, Kazakhstan, Lithuania, Moldova, Russia and Ukraine have high adult.[72] By any standard, “racially disadvantaged” groups fail to have "a state of complete physical, mental and social well-being"[65] and that failure is tied to race and not merely wealth.[59,48]

The current health disparity issues are not isolated health system problems. In fact, the health disparity is the cumulative result of both past and current racism. For instance, because of institutional racism, in general “racially disadvantaged” groups have less education and fewer educational opportunities; “racially disadvantaged” groups are disproportionately homeless and have significantly poorer housing options; and “racially disadvantaged” groups disproportionately work in lowest pay and high health risk occupations.

Another aspect of the health status dispartieis is between the “racially privileged” countries and “racially disadvantaged”. There is a significant economic gap between the so-called developing world and the developed world. And that economic gap is traceably in significant part to colonialization, slavery and neo-colonial policies and practices. An important aspect of the economic gap is the huge disparity in the health conditions. Furthermore, the physical and economic burdens of diseases affect peoples in the “racially privileged” countries more significantly than they do those in “racially disadvantaged” countries. In its 1999 World Health Report, the World Health Organization (WHO) stated that "[d]espite the long list of success in health achieved globally during the 20th century, the balance sheet is indelibly stained by the avoidable burden of disease and malnutrition that the world's disadvantaged populations continue to bear."[66] What WHO doesn’t comment on is how that disadvantaged is tied, for the most part, to racism.

In general, overall health status has improved in many ”racially disadvantaged” countries as life expectancies increase and infant mortality rates decrease. However, the disparities between life expectancy and infant mortality for the “racially privileged” and “racially disadvantaged” is still very significant.[66] In fact, in some aspects, health status is getting worse. HIV/AIDS crisis is spreading and deepening;[58] water-borne diseases such as cholera continue to cause illness and death;[52] and bacterial based illnesses such as malaria, pneumonia and tuberculosis are developing significant resistance to antibacterial drugs.[66]

Furthermore, despite significant health status disparities, individuals are denied equal access to quality health care on the basis of race. For instance, in the United Kingdom, Caribbean men are less likely to be registered with a general practitioner than white.[73] Whites are three times more likely to undergo bypass surgery than non-Whites.[74] Non-White patients seeking admission to nursing homes experience longer delays before placement than White patients.[45] Doctors are less likely to recommend breast cancer screening for Hispanic women than for White women.[74] Non-White pneumonia patients receive fewer hospital services than White patients.[74] Finally, poor urban Black and Hispanic neighborhoods average 24 physicians per 100,000 people, compared to 69 physicians per 100,000 for poor White communities.[74]

This denial of health care does not occur only as overt racism, but also as a result of institutional racism. This institutional racism is the result of the disparate impact of practices and policies, inadequate laws and regulations and ineffective enforcement of existing laws and regulations, cultural incompetence of health care providers and institutions, and socioeconomic inequities that are disproportionately distributed along racial lines. These factors contribute to "racially disadvantaged" groups having disparities in health status, unequal access to health care services, insufficient participation in health research or exploitation in health research and insufficient receipt of health care financing.

Racial Discrimination in Health Care

Racial discrimination is both overt and covert and it takes two closely-related forms:

individuals from "racially privileged" groups acting against individuals from "racially disadvantaged" groups, and acts by "racially privileged" community or country against "racially disadvantaged" community or country which has the intent of maintaining privilege;

policies, practices, regulations and laws that , when implemented, have a disparate negative impact on individuals from "racially disadvantaged" groups, communities or countries.

These constitute 'individual racism and institutional racism'. Individual racism consists of overt acts which causes death, physical, mental or economic injury or the destruction of property. Institutional racism is less overt, or more subtle, less identifiable in terms of specific individuals or countries committing the acts. But, it is no less destructive. Institutional racism originates in the operation of established and respected forces in the society or world and is instrumental in maintaining privilege, and thus receives far less public condemnation than individual racism.

When white terrorists bombed a black church and killed 5 black children, that is an act of individual racism, widely deplored by most segments of the society. But, . . . [when] black babies die each year because of the lack of proper food, shelter, and medical facilities, and thousands more are destroyed and maimed physically, emotionally, and intellectually because of conditions of poverty and discrimination in the black community, that is the function of institutional racism.[14]

Individuals from "racially disadvantaged" groups are sicker than individuals from "racially privileged" groups. Knowing that does not explain why and it certainly does not indicate the presence of institutional racism. To understand the role of institutional racism in health status requires an understanding of how health status is determined.[45] Clearly, many things affect health status. An individual's personal lifestyle choices affect health status because they affect an individual's personal behavior and psycho-social health, which affect his or her health. Physical environment and biology also affect health status. Health care institutions affect health status because both personal behavior and human biology are affected by an individual's access to health care, and by the quality of health care the individual receives from health care institutions.[31,45]

Class or Poverty theory maintains that the primary factor affecting differences in health care status between racial groups is socio-economic.[i][45] According to the class theory, poverty affects life-style, psycho-social behavior, personal behavior, human biology, physical environment, access to health care, and the behavior of the system and its institutions toward the individual. According to the class theory, it is lack of money, not racism, that explains the disparity in health.

Certainly, access to health care services is related to the financial capabilities of an individual or a country. The class theory, however, oversimplifies the issue and completely ignores the independent role of racial discrimination and neocolonialism that is based on racism.[18,41,45,64] Racial discrimination influences not only life-style, personal behavior, psycho-social behavior, physical environment, and biology, but also economics. Thus, racism has a double influence.

Racial discrimination establishes separate and independent barriers to health care institutions and to health care. To understand the impact of racial discrimination on health and health care there must be a developed knowledge base. The country with the most developed body of knowledge related to race and health care is the United States. The research from the United States clearly demonstrates that within a country, racial barriers to quality health care may manifest themselves in a number of ways:

[1]*Lack of Economic Access to Health Care*. Over 42 million Americans are uninsured with no economic access to health care. As access to health insurance in the United States is most often tied to employment, racial stratification of the economy due to other forms of discrimination has resulted in a concentration of “racially disadvantaged” groups in low wage jobs. These jobs are almost always without insurance benefits. As a result, disproportionate numbers of individuals from “racially disadvantaged” groups are uninsured with no economic access to health care.

[2]*Barriers to Hospitals and Health Care Institutions*. The institutional/structural racism that exists in the United States hospitals and health care institutions manifests itself in (1) the adoption, administration, and implementation of policies that restrict admission; (2) the closure, relocation or privatization of hospitals that primarily serve “racially disadvantaged” communities; and (3) the continued transfer of unwanted patients (known as "patient dumping") by hospitals and institutions to underfunded and over burdened public care facilities. Such practices have a disproportionate effect on “racially disadvantaged” groups; banishing them to distinctly substandard institutions or to no care at all.

[3]*Barriers to Physicians and Other Providers.* Areas that are heavily populated by “racially disadvantaged” groups tend to be medically undeserved.[45] Disproportionately few physicians from “racially privileged” groups have their practices located in “racially disadvantaged” communities. In fact, physicians from “racially disadvantaged” groups are significantly more likely to practice in “racially disadvantaged” communities, making the education and training of individuals from “racially disadvantaged” groups crucial. Yet, due to discrimination in post-secondary education, racial biases in testing and quality of life issues affecting school performance, “racially disadvantaged” groups are seriously under represented in health care professions.[45] The shortage of professionals from “racially disadvantaged” groups affects not only access to health care but also access to the power and resources to structure the health care system, leaving its control almost exclusively in hands of individuals from “racially privileged” groups. The result is a system that benefits the “racially privileged” at the expense of others.

---

[i] When individuals are separated into different racial population groups, there is general recognition of a health disparity between them. The explanation usually given for this disparity is that differences exist in socioeconomic status or class.

[4]*Disparities in Medical Treatment.* Differences in health status can also reflect inequities in preventive care and treatment. For instance, in the United States, African Americans are more likely to require health care services than European Americans, but are less likely to receive them.[45] In fact, racial disparity in treatment has been well documented. Studies have shown racial disparity in both quality and availability of treatment in AIDS,[19] cardiology,[50] cardiac surgery,[40] kidney disease,[22] organ transplantation,[27] internal medicine,[67] obstetrics,[61] prescription drugs,[30] treatment for mental illness,[60] and hospital care.[12]

In the United States, there are marked differences in time spent, quality of care and quantity of doctor's office visits between whites and blacks. Even when controlling for income, education, and ability to pay, Whites are more likely to receive more and more thorough diagnostic work and better treatment and care than people of color. Furthermore, researchers have concluded that doctors are less aggressive when treating patients from "racially disadvantaged" groups.[45] At least one study indicated a combined affect of race and gender resulting in significantly different health care for African American women than white women and men.[45]

Certainly, difference in treatment is based on a number of different factors including clinical characteristics, income, medical or biological differences. Nevertheless, race plays an independent role,[29] and of all the influences on the health of "racially disadvantaged" groups, it is imperative that health care systems be free of racial discrimination - both individual and institutional.[45]

[5]*Discriminatory Policies and Practices.* In the United States, discriminatory policies and practices can take the form of "medical redlining",[ii] excessive wait times, unequal access to emergency care, deposit requirements as a prerequisite to care, and lack of continuity of care. Discriminatory practices and policies often appear racially neutral but disproportionately affect "racially disadvantaged" groups.

For example, refusal to admit patients who do not have a physician with admitting privileges at that hospital, exclusion of Medicaid[iii] patients from facilities, and failure to provide interpreters and translations of materials, to name a few."[45] One significant example, is the United States federal Medicaid "racially neutral" policy that limits the number of beds a nursing home can allocate to Medicaid recipients. The indirect effect of the policy is to encourage these facilities to move existing patients who have spent all their assets and are now newly eligible for Medicaid into "Medicaid beds" as they become available.

It is mostly middle-class white women who have the assets to afford long term care without Medicaid, live long enough to spend down those assets, and become eligible for Medicaid. Thus, unintended effect of this policy is that there are fewer resources spent on "racially disadvantaged" populations for nursing home care even though they represent a larger portion of the Medicaid population and have more illness. In Medicaid, it is the combination of over-representation of individuals from "racially disadvantaged" groups in the program coupled with the government under-spending that is yet another example of the kind of structural and institutional racial discrimination that can persist unnoticed and uncorrected in many areas of an health care system.

[6]*Lack of Language and Culturally Competent Care.* A key challenge in a non-homogeneous society is to establish clear standards for culturally competent health care. Culturally competent care is defined as care that is "sensitive to issues related to culture, race, gender, and sexual orientation."

[ii] Medical redlining is the excluding of key medical services from predominantly communities whose members are from "racially disadvantaged" groups and concentrating them in the communities of the "racially privileged".

[iii] Medicaid is the a United States government health insurance program for the poor and disabled.

Cultural competency involves ensuring that all health care providers can function effectively in a culturally diverse setting; it involves understanding and respecting cultural differences.[45]

One example of institutional barriers to culturally competent care is the prevalence of linguistic barriers and the failure to use bilingual staff.[45] The failure to use bilingual, professionally and culturally competent staff in patient/client contact positions results in lack of access, mis-communication and mistreatment for those with limited proficiency in the dominant language. This includes not providing education or information at the appropriate literacy level. Furthermore, laws that restrict access to public services to those with proficiency in the dominant language -- also have acute and racially disproportionate impact on “racially disadvantaged” groups.

[7]*Impact of the Intersection of Race and Gender.* The unique experiences of the women from “racially disadvantaged” groups have been largely ignored. These women share many of the problems experienced by “racially disadvantaged” groups, in general, and women, as a whole. However, race discrimination and sex discrimination intersect to magnify the barriers women from “racially disadvantaged” groups face in gaining equal access to quality health care.[45] This intersection or "magnified impact" affects provision of treatments, access to medical care and inclusion in research. This is partly the result of different expectations of medical care between men and women and of gender bias among health care providers. Furthermore, these barriers are exacerbated in the case of gender-specific illnesses.[45]

Policies and practices that increase government surveillance and control of women from “racially disadvantaged” groups are also a key factor in health status. Women from “racially disadvantaged” groups are less likely to receive sympathetic intervention by law enforcement in the case of domestic violence. For instance, in the United States, there are numerous cases of women who, after calling upon police for help in such cases, are victims of both domestic violence and police violence.

In the United States, family planning is another area where public policy has had a negative impact on health status and life choices of women from “racially disadvantaged” groups. These women do not have equal access to preventive medicine or the full range of birth control. Barriers include lack of family planning services or facilities in their communities; lack of coverage of certain services, medications or procedures by other publicly funded health insurance programs; and disproportionately higher prescription of medically risky or unnecessary procedures such as contraceptive implants or forced sterilization. State and local policies are more likely to be discriminatory than federal policies. However, there are few standards for ensuring equal access and equal treatment at this level of government. In the United States, jurisdiction over the family planning area is increasingly devolving to the state and local level, which means that there is a critical need for