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IN THE 21ST CENTURY



## TRACK 7 – DRAFT PAPER

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*Racial and Ethnic Disparities in Health Status:  
Framing an Agenda for Public Health  
and Community Mobilization*

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***Introduction: Discovering Racial and Ethnic Disparities in Health***

Critical attention to racial and ethnic disparities in health status in recent years has revealed important questions for many in our society who are focused on health and social status, including public health officials, anthropologists and sociologists of health care, historical epidemiologists, other health care researchers, and community and social activists. A proliferation of interdisciplinary social science and epidemiological analytical frameworks in the health research literature continue to invite answers to core dilemmas: What is the meaning of race and ethnicity in health? What value do the categories race and ethnicity have for our strategies to reduce and eliminate social disparities in access to high quality preventive and primary health services? How do we build systems and networks of care that are sensitive to difference and the multiple identities of health care consumers? And finally, how do we translate current research about racial and ethnic disparities in health status into effective community-based strategies?

With its explicit call for a more active public health agenda to address health disparities between whites and various “minority” populations, the 1985 *Report of the Secretary’s Task Force on Black and Minority Health* presented new threshold questions about health care access, social disparities in health, civil rights, and accountability in public health and medicine in its declaration that there were identifiable “excess deaths” for African Americans, Hispanics, Native Americans, and Asian and Pacific Islander communities (Nickens 1986; US DHHS 1985). Excess deaths were defined as the difference between minority deaths and age- and sex-specific deaths for whites. At bottom, the report – the result of a Task Force on Black and Minority Health convened in

1984 by US Department of Health and Human Services Secretary, Margaret Heckler- identified six areas for special attention, given their high representation in the overall percentage of excess deaths: cancer; cardiovascular disease and stroke; chemical dependency (link with cirrhosis); diabetes; homicide, suicide, and unintentional injuries; and, infant mortality. Among the core strategies recommended for implementation, preventive health education, health professions investment, better research efforts targeted at minority groups, and more collaborative strategies were the most prominent.

Sixteen years after the release of the 1985 *Report on Black and Minority Health*, public health officials, researchers, community activists, and members of these groups are faced with some of the same health issues and similar dilemmas about strategy to eliminate gaps in access, care, and health status. Similarities do exist in the leading causes of death for members of all identified racial and ethnic groups, but there remains a disproportionate impact of HIV/AIDS among communities of color, for example [see *Appendix A*]. And although all groups have benefited from broader overall societal declines over the last half century in the incidence of infant mortality and cardiovascular disease, for instance, declines have been marked by the production of disparities and patterns of disproportionate impact. The launch of President Clinton's and the U.S. Department of Health and Human Services' *Racial and Ethnic Disparities in Health Initiative* to reduce and eliminate disparities in six areas- infant mortality, diabetes, cardiovascular disease, cancer screening and management, HIV/AIDS, and childhood and adult immunizations- is a part of the core strategy to meet the objectives identified in the United States Public Health Services' *Healthy People 2010* framework. In September of 1999, the federal Centers for Disease Control and Prevention awarded \$9.3 million to 32

community coalitions who were addressing some aspect of the six targeted health conditions. This past February, Health and Human Services Secretary Donna Shalala also made a formal budget request for \$5 billion to establish a Coordinating Center for Research on Health Disparities at the National Institutes of Health to foster a more coordinated and collaborative research and policy framework focused on minority health.

Again, more aggressive policy and research initiatives focused on minority health have flowed from a recognition that different communities have experienced a disproportionate impact from several health conditions, and that disparities exist even when there have been marked improvements in health status of the entire U.S. population. Life expectancy continues to reflect this pattern. Although life expectancy has risen for all groups in the U.S. population and racial and ethnic gaps have narrowed over the past century, there has been a consistent disparity in life expectancy in terms of race and ethnicity. In 1996, life expectancy at birth for black men was 66.1 years- the lowest for any group- and 73.9 for white men. These are among some of the starkest findings on racial and ethnic disparities in the six priority areas highlighted in the U.S. Department of Health and Human Services' Initiative:

- **Diabetes.** African Americans experience diabetes at a rate that is 70 percent higher than white Americans. The prevalence of diabetes among Hispanics is double that of white Americans. Data from 1994-1996 reveal that American Indian and Alaska Natives experience a diabetes death rate that 3.5 times greater than the rest of the U.S. population.
- **HIV/AIDS.** Minority communities, which account for 25% of the total U.S. population in official estimates, make up 50% of all AIDS cases.

AIDS is the leading cause of death for African Americans between the ages of 25 and 44 and the second leading cause of death for Hispanics in the same age group. It is also the fourth leading cause of death for African Americans and the fifth leading cause of death for Hispanics. African American and Hispanic women, who represent less than 25% of all U.S. women, account for 76% of AIDS cases among women through 1997.

- **Infant mortality.** In 1998, the overall U.S. infant mortality rates was 7.2 deaths per 1,000 live births. African Americans experience a rate that is 13.7 per 1,000 live births, while Hispanics experience a rate of 6 deaths per 1,000. Between 1985 and 1996, infant mortality rates by 33.7% for infants born to white mothers and declined by 22.6% for black infants during the same period. There are also racial and ethnic gaps in births to low birthweight infants, which constitute a risk for infant mortality.
- **Immunizations.** Seventy-nine percent (79%) of white children receive the complete series of critical vaccines by age two, while 74% of African American children and 71% of Hispanic children receive the same regimen. American Indians and Alaska Native children experience an immunization rate of 88% at the same age.
- **Cancer screening and Management.** In terms of mortality for men and women, African Americans have a cancer death rate that is 35% higher than whites. African American women, who are less likely to be diagnosed with breast cancer than white women, have a higher mortality rate. The lung cancer death rate is 27% higher for African Americans than for whites.

Prostate cancer reflects a similar disparity, with African American men experiencing a mortality rate twice that of white men. In terms of cervical cancer, Vietnamese women in the U.S. experience a rate that is five times greater than that of white women.

- **Cardiovascular disease.** In comparison to whites, coronary heart disease mortality is 40% below the rate for whites. African Americans, however, experience a rate that is 40% higher than that of whites.

Although it has not been singled out in the current U.S. Department of Health and Human Services' Race and Health Initiative, violence (including homicide and suicide), as well as unintentional injury, were mentioned in the 1985 report on black and minority health. This is an area, however, that warrants special mention, but is probably also a politically volatile issue, given the specter of gun control as a public health intervention and policy option to stem incidence. Between 1985 and 1996, age-adjusted firearm injury death rates for Black males increased 23.2 percent compared to 7.2 percent for White males. In 1996, Black males aged 15 to 24, for whom death from homicide and legal intervention is the leading cause of death, experienced a death rate from this cause of 123/ per 100,000 compared to 49 for Hispanics, 27 for Native Americans, 16 for Asian Americans, and 14 for Whites. Domestic violence, an area that has been explored in greater detail in recent years, has also reflected disparities. Between 1992 and 1996, the average annual rate of nonlethal violent victimization by an intimate per 1,000 stood at 8 for whites, 12 for blacks, and 7 for Hispanics.

Even as attention to racial and ethnic disparities in health is sustained in prominent local, state, and federal public health campaigns, it is important to note at the

outset that there are a host of problems related to the measurement of racial and ethnic disparities. These include the inconsistency in definitions of race and ethnicity, the lack of consistent state and federal data for major groups (Native Americans and Asian and Pacific Islander communities, in particular), and a general homogenization of cultural, class, and ethnic experiences within these diverse communities. Some of our main national surveys measuring health care access, utilization, and status, including the *Current Population Survey* (CPS), the *Medical Expenditure Panel Survey* (MEPS), the *National Health Interview Survey* (NHIS), and the *Behavioral Risk Factor Surveillance System* (BRFSS) have major gaps in the experiences of communities that are not identified as black, white, or Hispanic (Bolen et.al 2000). Nor do these surveys often recognize complex ethnic group identities, such as Puerto Rican, Dominican, or Mexican, within broader categories such as Hispanic. Efforts to reduce and eliminate disparities must journey beyond simple categorization to affirm the ways in which race, as most geneticists and social scientists now affirm, is not a valid biological formulation but a culturally-constructed social reality. In this context, researchers and community activists must constantly search for the diverse socioeconomic variables, such as income, education, transnational experience, acculturation, etc.. that often mask the diverse cultural contexts and identities that underlie so-called racial and ethnic group categorization. Historically, racial categorization has been used simultaneously to stigmatize and discriminate, at the same time that it has been invoked to critique and fight discrimination and oppression.

***Race and Ethnic Differentials in Health: An Assessment of  
Contributory Factors***

Disparities in health status for racial and ethnic groups have been traced to many factors, including socioeconomic factors (e.g., income, poverty, educational level, employment, acculturation, etc...), racism and gender discrimination, and other contextual factors such as insurance coverage and access to high quality networks of preventive and primary care (Bollini, et.al 1995; Cooper, et.al 1981; Muntaner, et.al 1997). Poverty has been recognized a major barrier to access among racial and ethnic groups, given its disproportionate impact on communities of color. A major contributory factor in recent years stems from the reality that racialized communities are also spatialized in terms of the urban environment, where unique nonfinancial and financial barriers to access in recent years have included concentrated poverty, a shortage and maldistribution of primary care providers, a hesitancy to accept Medicaid, lack of indigent or charity care facilities, variability in quality and choice of care options, as well as influences from the broader political trends of immigration and welfare reform. In addition, researchers have just begun to unravel the ways in which the issue of expanding devolution of federal public health and social service programs is impacting racial and ethnic differentials in social and economic status, as states exercise options to determine eligibility with limited federal prescriptions. I will return to a discussion of Medicaid, the state-administered health insurance program for the medically needy, to illustrate this point.

### *Financial Barriers*

Poverty is a major factor in the experience of racial and ethnic groups in the United States, as well as a significant financial barrier to access. In 1998, the U.S. Census Bureau reported that 12.7% of the population lived below the poverty level. It reported that 10.5% of Whites, in comparison to 26.1% of Blacks, 25.6% of Hispanics, and 12.5% of Asian and Pacific Islander communities lived under the poverty level. While the Medicaid program has been highlighted as a major factor in the provision of comprehensive services to poor and marginalized communities of color since 1965 and helped to narrow racial and ethnic gaps in prenatal care, infant mortality, and other health conditions, it is estimated that eligibility significantly lags behind enrollment.

Approximately 4 million children, the United States Department of Health and Human Services estimates, are eligible for Medicaid but not enrolled. This fact inhibits access to much-needed services. Health care coverage is an important issue determining access and has been associated with the maintenance of a regular source of care, access to after hours emergency care, and sustained contact with a physician or comprehensive system of preventive and primary care services (Targanski, et.al 1994; Crump, et.al 1999).

Recognized as a major financial variable for health care access, insurance status is key to the eradication of social disparities in health. There have been observed trends in racial and ethnic disparities in health coverage. The March 1999 Supplement to the *Current Population Survey* reports that 15.5% of Whites, 22.2% of Blacks, 21.1% of Asian and Pacific Islanders, and 35.3% of those of Hispanic origin went without health

insurance for the entire year of 1998. In terms of the experiences of children, 14.4% of White children, 19.7% of black children, 30.0% of Hispanic children, and 16.8% of Asian and Pacific Islander children went without coverage for 1998. These findings are also consistent with other national surveys.

While the U.S. Census Bureau affirms that 70.2% of Americans are covered by private insurance through employers, Medicaid enrollment data reveals that it is an important source of coverage for the poor and communities of color. According to a recent report from the California-based Kaiser Family Foundation, one-half of Medicaid's 1997 beneficiaries were white and half were minority. Of those living under 200% of the federal poverty level, Medicaid covered 39% of African Americans and 36% of Native Americans. The program also covers 1 in 5 nonelderly African Americans, Latinos, and Native Americans, in comparison to less than 1 in 10 nonelderly whites. The same report also found that minority Medicare beneficiaries were more likely to use Medicare as a sole source for insurance protection. The Kaiser Survey also highlighted that 25% of African American and Latino beneficiaries had no supplemental coverage, in comparison to 10% of whites.

It is also important to note that there are gaps in access to health care coverage for the poor and minority communities work full-time. A recent Commonwealth Fund survey on the availability of employer-sponsored coverage found racial and ethnic gaps in access to coverage. Twenty-nine (29%) of Hispanic full-time, low-wage Hispanic workers lacked an opportunity to participate in employer-sponsored plans, in comparison to 14% of Blacks and 12% of Whites who were also not afforded an opportunity for coverage. This is an especially troubling fact, given the growth in the number of the

uninsured to 44.6 million, the increasing gap in insurance coverage between low-wage and high-wage workers, and the rates of erosion of employer-based coverage in general. Cooper and Schone (1997) found that in 1996 55% of low-wage workers (defined as those earning \$7 or less an hour) had access to employer-sponsored health insurance, in comparison to 96% of high-wage workers (those earning \$15.01 or more an hour). Scholars who have studied patterns in the erosion of employer-based coverage, such as Newacheck (1997) and Long and Marquis (1999), have also identified that Hispanics constitute approximately 30% of those who experienced the erosion of employer-based during the mid 1990s.

*Nonfinancial: Cultural and Contextual Barriers*

There are significant nonfinancial barriers bearing on contextual factors, such as cultural competency, racism, classism, sexism, xenophobia, linguistic diversity, acculturation, and other issues that shape interactions with health care providers and institutions (Gamble 1989; Guralnik 1997). There are also other factors that inhibit access to health care, even when insurance coverage is not the issue. For example, numerous surveys underscore that minority children often have longer travel times to get to sites of care and that they have longer wait times when seeing a health care provider. At bottom, a greater understanding of these cultural and contextual factors is needed to understand barriers to access preventive and primary care services. These contextual factors have implications for the study of asthma hospitalization rates in New York City, for instance, where African American and Latino children are two to three times more

likely to die from asthma than white children. Health care researchers continue to note differentials across all income groups and in comparisons of experiences of black and white Medicaid beneficiaries with similar visits and prescriptions.

Cultural differences and appreciation of diversity in the process of accessing and maintaining services has been shown to be a key factor in patterns of health care delivery. Racism, discrimination, and xenophobia are at the heart of interactions with the health care system, as demonstrated by numerous surveys and scholarly analyses. A *recent Comparative Survey of Minority Health* sponsored by the Commonwealth Fund found that language differences were a problem for 21% of minority Americans in seeking care. The survey found that 26% of Hispanic adults and 22% of Asian American adults who did not speak English as a first language needed an interpreter when seeking care. Similar studies of consumers by the Kaiser Foundation found that there were issues of distrust of the health care system by African Americans, some of whom carried the historical memory of the Tuskegee Syphilis Study (1932-1972) and its race and class dynamics in the framing of medical experimentation on African Americans (Gamble 1999). In the Kaiser study, consumers expressed that they were stereotyped through ideas that African Americans, Native Americans, and Hispanics were all poor, African American women were all unmarried, and that Asians were deferential, among other common and offensive ideas.

There is compelling evidence that racism and ideas about racial and ethnic difference impact not only the view of patients by providers, but also the pattern of treatment. Fifteen percent (15%) of minority participants in the recent Kaiser study, who echo other surveys and were more likely to report that their health was poor in

comparison to whites, expressed a belief that they would have received better care during the previous year if they were of a different race. A series of popular articles on the impact of race on physician recommendations for cardiac catheterization have underscored as well that patterns of treatment may stem from a conscious or unconscious belief about race. A study by Schulman et.al (1999) is particularly illuminating for cardiovascular disease management in its finding that blacks and some women were less likely to be referred for cardiac catheterization, coronary-artery bypass graft surgery when presenting chest pains or myocardial infarction, even when one controls for insurance status and other interactions with health care providers.

### *An Agenda for Public Health and Community Action*

While there is certainly a need for disease-specific strategies [perhaps we can explore some case studies in final version] that stem from an appreciation of a unique constellation of medical and social factors in the incidence of various diseases, there are broader policy options that go beyond the traditional community-based public health strategies which have implications for racial and ethnic disparities (Institute of Medicine 1987; Brooks 1997; Krieger 1999). I will focus in this next section on community action and themes that will be necessary to deal with current trends in health care delivery and financing which impact minority health (New York Academy of Medicine 1999, 2000).

- **Social Justice.** Community and health care activists must mobilize to promote public policies which are just and fair. This implies that they are free from the

effects of discrimination. This also implies an end to punitive xenophobic policies that exclude newly-arrived immigrants and certain classes of citizens from comprehensive systems of care. There are powerful historical examples, in terms of the exclusion of blacks and early twentieth century Catholics and Eastern, Central, and Southern European immigrants from segregated and nativist health care institutions. Legal challenges to segregation in health care waged through *Simkins v. Cone* (1963) and other cases presented compelling evidence that racial covenants excluding certain classes of patients, as well as the maintenance of segregated health care institutions (e.g., Hill-Burton hospital construction funds, etc...), undermined the health status of marginalized groups.

The denial of publicly-sponsored health care to newly-arrived immigrants and certain classes of citizens under welfare and immigration reform should be addressed from an ethical perspective. The implementation of the Personal Responsibility and Work Reconciliation Act of 1996 (PRWORA), in this context, has had dramatic implications in urban areas for racialized and spatialized communities. Diversion practices instituted for potential Medicaid and food stamp populations have been pointed out in documents from the U.S. Department of Health and Human Services and the Justice Department's Office of Civil Rights (see [www.hcfa.gov](http://www.hcfa.gov) for "Dear State" letters from Center for Medicaid and State Operations).

*Strategy:* Health care advocates and community-based organizations should work together to insure that discriminatory policies are not implemented on the federal,

state, or local level. Discriminatory practices should be tracked and reported to the U.S. Department of Justice and the U.S. Department of Health and Human Services, Office of Civil Rights.

- **Development of cultural competency assessment instruments and materials for Outreach.** A voluminous social science and epidemiologic literature has provided evidence that nonfinancial barriers to health care stem from low levels of cultural competency among providers and problems of translation stemming from linguistic and cultural diversity [see *Appendix B* for resources/contacts]. Developmental models of ethnosensitivity, which measure ethnocentrism, can help to assess an institution's effectiveness in dealing with various populations and quality of care.

*Strategy:* An important model of this process has been implemented at the New York Academy of Medicine, where an interdisciplinary and multisectoral network of health providers, researchers, and community activists convene in a Racial Disparities in Health Workgroup share advice and experiences related to cultural competency and institutional practices [see *Appendix C*]. These discussions have implications for the delivery of services. At the Sunset Park Health Center and the Downtown Family Care Center in New York, for example, there are social and cultural assessments of Latino immigrants, which measure acculturation and various other cultural beliefs and practices. This information is gathered at the Downtown Family Care Center and integrated in medical school curricula.

- **Insurance coverage: Medicaid/XIX and SCHIP/Title XXI.** Medicaid and the State Children’s Health Insurance Program represent important opportunities to sustain gains in minority health status, as well as options to narrow racial and ethnic disparities in the future (Ferguson 1997a; Weinick, et.al 1998). The continued devolution of authority and oversight in public health and social welfare programs to the states coupled with welfare reform represents a dilemma for access in some states. SCHIP, in particular, where states can expand Medicaid or create their own state-only child health insurance programs, gives states extreme flexibility in the determination of eligibility criteria, including the use of geography/residence. States may also exercise extreme autonomy in the creation of benefit packages in their new state-only programs, a fact reflected in the wide variation of services currently offered among the states that participate in Title XXI. States have the option to include additional and optional services, such as substance abuse prevention, mental health services, and translation assistance.

*Strategies:* (1) Health advocates, providers, and community-based organizations should aggressively maintain educational programs about continued eligibility for Medicaid in the aftermath of PRWORA’s passage. Welfare reform de-coupled eligibility for Medicaid based on welfare enrollment, and current declines in Medicaid caseloads parallel, in some instances, dramatic declines in welfare caseloads. The federal Administration for Children and Families (ACF), the agency responsible for oversight of the new Temporary Assistance to Needy Families (TANF) program, reports that the number of families receiving TANF declined from

4,114,000 to 2,536,000 during the period between January 1997 and June 1999.

While state experiences differ in many respects, Medicaid participation rates declined. One study by Ellwood and Wu (1998) found that Medicaid cases dropped by almost 30% in Wisconsin and 20% in New York between January 1995 and January 1998. Given the importance of Medicaid as a financing mechanism for the poor and minority communities, Medicaid and SCHIP enrollment monitoring is important strategies to preserve access. Advocates should encourage states to use the \$500 million Medicaid/TANF outreach fund to educate communities and hire eligibility workers to enroll people who are Medicaid-eligible in the aftermath of welfare reform. (2) Specifically in the case of SCHIP, health care providers and community-based organizations should monitor their State Plan development processes to determine the services that are being inserted in benefits packages (as well as potential fees and fines). This should also imply a monitoring of the decision about whether to expand Medicaid under Title XXI or to restrict benefits. The flexibility to establish eligibility based on geography also has implications for the politics of race, place, and health.

- **Research.** Research is needed about the complex composition of various identified racial and ethnic groups, including subgroups and cultural communities within the currently invoked broad categories. What other health conditions reflect differences in communities, such as the divergent experience with asthma hospitalization patterns of Puerto Rican and Mexican American children (Puerto

Rican children experience a prevalence of 11% in comparison to 3% among Mexican American children).

*Strategy:* (1) Promote more interdisciplinary research frameworks that bring together a diverse network of scholars and practitioners from varied backgrounds. (2) Establish special journal issues that highlight dilemmas related to race and ethnicity. (3) Refine data on specific under-represented communities, such as Asian and Pacific Islander communities and Native American communities, in research and evaluation.

- **Other Issues for Discussion:**

- (1) Balance between prevention and treatment.
- (2) Health professions development. Attention to under-representation in medical and allied health schools. Attention to disproportionate impact of practice among poor among minority physicians.
- (3) Policy and leadership development for health care providers.

