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ELIMINATING RACIAL DISCRIMINATION IN HEALTH CARE: A CALL FOR STATE HEALTH CARE ANTI-DISCRIMINATION LAW

Vernellia R. Randall, JD, MSN

“It might be that civil rights laws often go unenforced; it might be that current inequities spring from past prejudice and long standing economic differences that are not entirely reachable by law; or it might be that the law sometimes fails to reflect, and consequently fails to correct, the barriers faced by people of color.”

--Derrick Bell¹

Equal access to quality health care is a crucial issue facing the United States (“US”).² For too long, we have denied too many Americans equal access to quality health care based on race, ethnicity, and gender.³ Many factors contribute to inequities: cultural incompetence of health care providers, socioeconomic inequities, disparate impact of facially neutral practices and policies, inadequacy of civil rights laws and enforcement, and multiple forms of discrimination. These inequities exist in health status, access to health care services, participation in health research and

¹ DERRICK A. BELL, JR., *AND WE ARE NOT SAVED: THE ELUSIVE QUEST FOR RACIAL JUSTICE* 52 (Basic Books 1987) [hereinafter *NOT SAVED*].

² *See, e.g.*, COMMITTEE ON UNDERSTANDING AND ELIMINATING RACIAL AND ETHNIC DISPARITIES IN HEALTH CARE, INSTITUTE OF MEDICINE, *UNEQUAL TREATMENT: CONFRONTING RACIAL AND ETHNIC DISPARITIES IN HEALTHCARE* (Brian D. Smedley, Adrienne Y. Stith & Alan R. Nelson eds., 2002), *available at* <http://www.iom.edu/?id=16740> (last visited June 26, 2002) [hereinafter *IOM REPORT*]; *see also* THE UNITED STATES COMMISSION ON CIVIL RIGHTS, *THE HEALTH CARE CHALLENGE: ACKNOWLEDGING DISPARITY, CONFRONTING DISCRIMINATION, AND ENSURING EQUALITY, THE ROLE OF GOVERNMENTAL AND PRIVATE HEALTH CARE PROGRAMS AND INITIATIVES* (Sept. 1999), *available at* <http://www.law.umaryland.edu/marshall/usccr/documents/cr12h34z.pdf> (last visited June 26, 2002) [hereinafter *U.S. COMMISSION ON CIVIL RIGHTS I*].

³ *See, e.g.*, W. MICHAEL BYRD AND LINDA A. CLAYTON, *AN AMERICAN HEALTH DILEMMA: A MEDICAL HISTORY OF AFRICAN AMERICANS AND THE PROBLEM OF RACE, BEGINNINGS TO 1900* (Routledge 2000) [hereinafter *AN AMERICAN HEALTH DILEMMA I*]; W. MICHAEL BYRD AND LINDA A. CLAYTON, *AN AMERICAN HEALTH DILEMMA: A MEDICAL HISTORY OF AFRICAN AMERICANS AND THE PROBLEM OF RACE, 1900 TO PRESENT* (Routledge 2002) [hereinafter *AN AMERICAN HEALTH DILEMMA II*]; *see also* U.S. COMMISSION ON CIVIL RIGHTS I, *supra* note 2.

receipt of health care financing.⁴ This inequity in health care is doubly significant given the devastating racial inequity in health status that exists. The combination of racial inequity in health status, institutional racism in health care and inadequate legal protection points to a need for a major civil rights law for health care.

I. INEQUITY IN HEALTH STATUS: BRIEF REVIEW

The need to focus specific attention on the discrimination inherent in the institutions and structures of health care is overwhelming. Racial minorities are sicker than white Americans; they are dying at a significantly higher rate. These are undisputed facts. Many examples of inequities in health status between racial/ethnic groups exist: infant mortality rates are 2½ times higher for blacks,⁵ and 1½ times higher for American Indians, than for whites;⁶ the death rate for heart disease for blacks is higher than for whites;⁷ 50 percent of all AIDS cases are among minorities who account for only 25 percent of the U.S. population;⁸ the prevalence of diabetes is 70 percent higher among blacks and twice as high among Hispanics as among whites;⁹ Asian Americans and Pacific Islanders have the highest rate of tuberculosis of any racial/ethnic group;¹⁰ cervical cancer is nearly five times more likely among Vietnamese American women than white women;¹¹ women are less likely than men to receive lifesaving drugs for heart attacks;¹² more women than men require bypass surgery or suffer a heart attack after an angioplasty.¹³

Yet, despite these significant health status inequities, we have denied many Americans equal access to quality health care based on race, ethnicity, and gender. Factors that contribute to this inequity in health care include the following: cultural incompetence of health care providers, socioeconomic inequities, disparate impact of facially neutral practices

⁴ See, e.g., U.S. COMMISSION ON CIVIL RIGHTS I, *supra* note 2; see also 2 THE UNITED STATES COMMISSION ON CIVIL RIGHTS, ACKNOWLEDGING DISPARITY, CONFRONTING DISCRIMINATION, AND ENSURING EQUALITY, THE ROLE OF FEDERAL CIVIL RIGHTS ENFORCEMENT (1999) [hereinafter U.S. COMMISSION ON CIVIL RIGHTS II].

⁵ U.S. COMMISSION ON CIVIL RIGHTS I, *supra* note 2, at 11.

⁶ *Id.*

⁷ *Id.* (147 deaths per 100,000 for blacks compared to 105 deaths per 100,000 for whites).

⁸ *Id.*

⁹ *Id.*

¹⁰ *Id.* at 31.

¹¹ *Id.*

¹² *Id.* at 14-15.

¹³ *Id.*

and policies, misunderstanding of civil rights laws, and discrimination contribute to inequities in health status, access to health care services, participation in health research, and receipt of health care financing.

Drs. Michael Byrd and Linda Clayton clearly laid out the long history of racism and medicine in their seminal work: "An American Dilemma: A Medical History of African Americans and the Problem of Race, Beginnings to 1900" and "An American Dilemma: A Medical History of African Americans and the Problem of Race, 1900 to 2000." In their work, Drs. Byrd and Clayton show that the problem of black health status and black health care access is a part of a long continuum of racism and racial discrimination dating back almost 400 years. In fact, since colonial times, the racial dilemma that affected America also distorted medical relationships and institutions.¹⁴ Throughout our history, we have actively assigned racial minorities to the underfunded, overcrowded, inferior, public health care sector.¹⁵

Historically, medical doctors and medical leadership helped to establish and maintain a racially discriminatory health care system. They helped to establish the slaveocracy, create the racial inferiority myths, build a segregated health subsystem, and maintain racial bias in the diagnosis and treatment of patients.¹⁶ Only after 350 years of active discrimination and neglect, were efforts made to admit minorities into the "mainstream" health system.¹⁷ However, these efforts were flawed and since 1975 minority health status has steadily eroded. Consequently, minorities continue to experience racial discrimination in access to health care and quality of health care received.¹⁸

Yet, current issues in health inequities are not isolated to problems in the health system. They are the cumulative result of both past and current racism throughout US culture. For instance, because of institutional racism, minorities have less education and fewer educational opportunities.¹⁹ Minorities are disproportionately homeless and have

¹⁴ AN AMERICAN HEALTH DILEMMA I, *supra* note 3; AN AMERICAN HEALTH DILEMMA II, *supra* note 3.

¹⁵ *Id.*

¹⁶ *Id.*

¹⁷ AN AMERICAN HEALTH DILEMMA II, *supra* note 3.

¹⁸ *Id.*

¹⁹ In 1993, the high school dropout rate for blacks was 12.6 and 28.6 for Hispanics compared to 7.3 for whites. NATIONAL CENTER FOR EDUCATION STATISTICS, U.S. DEPARTMENT OF EDUCATION, DIGEST OF EDUCATION STATISTICS Table 106 (2000), available at <http://nces.ed.gov/programs/digest/d00/dt106.asp> (last visited June 26, 2002); see also REBECCA GORDON, LIBERO DELLA PIANA & TERRY KELEHER, FACING THE CONSEQUENCES: AN EXAMINATION OF RACIAL DISCRIMINATION IN U.S. PUBLIC

poorer housing options.²⁰ Due to discrimination and limited educational opportunities, minorities disproportionately work in low pay, high health risk occupations (e.g., migrant farm workers, fast food workers, garment industry workers).²¹ Historic and present racism in land and planning policy also plays a critical role in minority health status.²² Minorities are much more likely to have toxic materials (and other unhealthy uses) sited in their communities than whites despite income.²³ For example, over-concentration of alcohol and tobacco outlets and the legal and illegal dumping of pollutants pose serious health risks to minorities.²⁴ Exposure to these risks is not a matter of individual control or even individual choice. It is a direct result of discriminatory policies designed to protect white privilege at the expense of minority health.

SCHOOLS (2000), *available at* <http://www.arc.org/content/view/293/36/> (last visited June 26, 2002); THE PERSISTENCE OF WHITE PRIVILEGE AND INSTITUTIONAL RACISM IN UNITED STATES POLICY, TRANSNATIONAL RACIAL JUSTICE INITIATIVE SHADOW REPORT CERD 38-41 (2001), *available at* http://www.thepraxisproject.org/tools/White_Privelege.pdf (last visited June 26, 2002) [Hereinafter "The White Privilege Shadow Report"]; U.S. COMMISSION ON CIVIL RIGHTS I, *supra* note 2, at 15-18.

²⁰ Home ownership among Hispanics nationally stands at 47.3 percent and at 47.7 percent for African-Americans, compared to 74.3 percent for the white, non-Hispanic. *See, e.g.,* Deborah Kenn, *Institutionalized, Legal Racism: Housing Segregation And Beyond*, 11 B.U. PUB. INT. L.J. 35 (2001); The White Privilege Shadow Report, *supra* note 19, at 46-71. 40% of homeless clients served were minorities. *See* HUD USER, HOMELESSNESS: PROGRAMS AND THE PEOPLE THEY SERVE-TECHNICAL REPORT (1999), *available at* http://www.huduser.org/publications/homeless/homeless_tech.html (last visited June 26, 2002); *see also* All Other Things Being Equal: A Paired Testing Study of Mortgage Lending Institutions 48 (April 2002) (finding that African American and Hispanic home buyers in both Los Angeles and Chicago face a significant risk of unequal treatment when they visit mainstream mortgage lending institutions to make pre-application inquiries); U.S. COMMISSION ON CIVIL RIGHTS I, *supra* note 2, at 15-18.

²¹ BUREAU OF LABOR STATISTICS, NUMBER OF NONFATAL OCCUPATIONAL INJURIES AND ILLNESSES INVOLVING DAYS AWAY FROM WORK BY INDUSTRY AND RACE OR ETHNIC ORIGIN OF WORKER (2000), <http://www.bls.gov/iif/oshwc/osh/case/ostb1071.txt> (last visited June 26, 2002); *see also* U.S. COMMISSION ON CIVIL RIGHTS I, *supra* note 2, at 18.

²² *See, e.g.,* The White Privilege Shadow Report, *supra* note 19, at 54-71; *see also* DOUGLAS S. MASSEY AND NANCY A. DENTON, *AMERICAN APARTHEID: SEGREGATION AND THE MAKING OF THE UNDERCLASS* 36 (Harvard Univ. Press 1993).

²³ *See, e.g.,* Jill E. Evans, *Challenging The Racism in Environmental Racism: Redefining The Concept of Intent*, 40 ARIZ. L. REV. 1219 (1998); *see also* U.S. COMMISSION ON CIVIL RIGHTS I, *supra* note 2, at 18-20.

²⁴ *See, e.g.,* Vernellia Randall, *Smoking, the African-American Community, and the Proposed National Tobacco Settlement*, 29 U. TOL. L. REV. 677 (1998); *see also* Kathryn A. Kelly, *The Target Marketing of Alcohol and Tobacco Billboards to Minority Communities*, 5 U. FLA. J.L. & PUB. POL'Y 33 (1992).

II. INEQUITY IN HEALTH CARE: A BRIEF REVIEW

Compounding the racial discrimination experienced generally, is the institutional racism in health care that affects access to health care and the quality of health care received.²⁵ Despite efforts to eliminate discrimination and reduce racial segregation over the past thirty years, little change in the quality of or access to health care for many minorities has occurred. According to the US Commission on Civil Rights:

“Despite the existence of civil rights legislation equal treatment and equal access are not a reality for racial/ethnic minorities and women in the current climate of the health care industry. Many barriers limit both the quality of health care and utilization for these groups, including . . . discrimination.”²⁶

Racial discrimination in health care delivery, financing, and research continues to exist, and racial barriers to quality health care manifests themselves in many ways including: lack of economic access to health care,²⁷ barriers to hospitals and health care institutions,²⁸ barriers to

²⁵ See, e.g., Marianne Engelman Lado, *Unfinished Agenda: the Need for Civil Rights Litigation to Address Race Discrimination and Inequalities in Health Care Delivery*, 6 TEX. F. ON C.L. & C.R. (2001); see also René Bowser, *Racial Profiling in Health Care: an Institutional Analysis of Medical Treatment Disparities*, 7 MICH. J. RACE & L. 79 (2001) [hereinafter *Racial Profiling*]; Vernellia R. Randall, *Slavery, Segregation and Racism: Trusting the Health Care System Ain't Always Easy! An African American Perspective on Bioethics*, 15 ST. LOUIS U. PUB. L. REV. 191 (1996) [hereinafter *Slavery, Segregation and Racism*]; Vernellia R. Randall, *Racist Health Care: Reforming an Unjust Health Care System to Meet the Needs of African-Americans*, 3 HEALTH MATRIX 127 (1993) [hereinafter *Racist Health Care*].

²⁶ U.S. COMMISSION ON CIVIL RIGHTS I, *supra* note 2, at 202.

²⁷ More than 43 million Americans are uninsured with no economic access to health care. A disproportionate number of the uninsured are racial minorities. 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 racial minorities in low wage jobs. These jobs are almost always without insurance benefits. As a result, disproportionate numbers of the uninsured are racial minorities. In fact, a disproportionate number of racial minorities have no insurance, are unemployed, and are employed in jobs that do not provide health care insurance, disqualify for government assistance programs, or fail to participate because of administrative barriers. Gaps in health status, and the absence of relevant health information, are directly related to access to health care.

²⁸ The institutional/structural racism that exists in hospitals and health care institutions

physicians and other providers,²⁹ racial discrimination in medical treatment,³⁰ discriminatory policies and practices,³¹ lack of language and culturally competent care,³² disparate impact of the intersection of race

manifests itself in the (1) adoption, administration, and implementation of policies that restrict admission; (2) the closure, relocation or privatization of hospitals that primarily serve the minority community; and (3) the continued transfer of unwanted patients (known as "patient dumping") by hospitals and institutions. Such practices have a disproportionate effect on racial minorities banishing them to distinctly substandard institutions or to no care at all.

²⁹ Areas that are heavily populated by minorities tend to be medically under-served. Disproportionately few White physicians have their practices located in minority communities. Minority physicians are significantly more likely to practice in minority communities, making the education and training of minorities extremely important. Yet, due to discrimination in postsecondary education, racial biases in testing and quality of life issues affecting school performance, minorities are seriously under represented in health care professions. The shortage of minority professionals 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 white hands. The result is an inadequate, ineffective and marginalized voice on minority health care issues.

³⁰ Differences in health status reflect, to a large degree, inequities in preventive care and treatment. For instance, African Americans are more likely to require health care services, but are less likely to receive them. Disparity in treatment has been well documented in a number of studies including studies done on AIDS, cardiology, cardiac surgery, kidney disease, organ transplantation, internal medicine, obstetrics, prescription drugs, treatment for mental illness, pain treatment and hospital care. *See, e.g., U.S. Slavery, Segregation and Racism, supra note 25; see also Randall, Racist Health Care, supra note 25.*

³¹ Discriminatory policies and practices can take the form of medical redlining, excessive wait times, unequal access to emergency care, deposit requirements as a prerequisite to care, and lack of continuity of care, which all have a negative effect on the type of care received. *See, e.g., U.S. COMMISSION ON CIVIL RIGHTS I, supra note 2, at 74-78; see also Sidney Watson, Reinvigorating Title VI: Defending Health Care Discrimination - It Shouldn't be so Easy, 58 FORDHAM L. REV. 939 (1990).*

³² A key challenge has been to get the Government 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." Vernellia Randall, *Does Clinton's Health Care Reform Proposal Ensure [E]Qual[ity] of Health Care for Ethnic Americans and the Poor?* 60 BROOK. L. REV. 167, 205-12 (1994). Cultural competency involves ensuring that all health care providers can function effectively in a culturally diverse setting; it involves understanding and respecting cultural differences. In addition to recognizing the disparities in health status between White Americans and minority groups, we must recognize differences within groups as well. Ethnic and racial minority communities include diverse groups with diverse histories, languages, cultures, religions, beliefs, and traditions. This diversity is reflected in the health care they receive and the experiences they have with the health care industry. Without understanding and incorporating these differences, health care cannot be provided in a culturally competent manner. *See, e.g., U.S. COMMISSION ON CIVIL RIGHTS I, supra note 2, at 52-54.*

and gender,³³ inadequate inclusion in health care research,³⁴ and rationing through managed care.³⁵

³³ The unique experiences of women of color have been largely ignored by the health care system. These women share many of the problems experienced by minority groups, in general, and women, as a whole. However, race discrimination and sex discrimination often intersect to magnify the difficulties minority women face in gaining equal access to quality health care. In addition to barriers restricting access to health care for racial/ethnic minorities, there are barriers to care that predominantly affect minority women. There are also gender differences in medical use, provision of treatments, and inclusion in research. This is partly the result of different expectations of medical care between men and women and of gender bias of health care providers. *See, e.g.,* U.S. COMMISSION ON CIVIL RIGHTS I, *supra* note 2, at 47-50; *see also* Lisa C. Ikemoto, *The Fuzzy Logic of Race and Gender in the Mismeasure of Asian American Women's Health Needs*, 12. 65 U. CIN. L. REV. 799 (1997); Diane E. Hoffmann and Anita J. Tarzian, *The Girl Who Cried Pain: a Bias Against Women in the Treatment of Pain*, 29 J.L. MED. & ETHICS 13 (2001); Michelle Oberman and Margie Schaps, *Women's Health and Managed Care*, 65 TENN. L. REV. 555 (1998); Carol Jonann Bess, *Gender Bias in Health Care: a Life or Death Issue for Women with Coronary Heart Disease*, 6 HASTINGS WOMEN'S L.J. 41 (1995).

³⁴ Despite volumes of literature suggesting the importance of race, ethnicity, and culture in health, health care, and treatment, there is relatively little information available on the racial, ethnic, and biological differences that affect the manifestations of certain illnesses and their treatments. In response to years of exclusion of minorities and women, several statutory requirements have been enacted to ensure that research protocols include a diverse population. The health condition of women and minorities will continue to suffer until they are included in all types of health research. *See, e.g.,* U.S. COMMISSION ON CIVIL RIGHTS I, *supra* note 2, at 109-117, Pub. L. No. 103-43, 107 Stat. 122 (codified in scattered sections of 8 and 42 U.S.C. (1994 & Sup II 1996)).

³⁵ The health care financing system has been steadily moving to managed care as a means of rationing health care. Without proper oversight, oversight that does not currently exist, managed care will, over time, tend to place increasingly stringent requirements on providers. They may fail to develop more expensive but culturally appropriate treatment modalities, and they may refuse or minimize the expenditures necessary to develop adequate infrastructure for minority communities. The potential for discrimination, particularly racial/ethnic discrimination to occur in the context of managed care is significant and is recognized as such by OCR and leading commentators and advocates for civil rights in health care services, financing, and treatment. However, little has been to protect minorities from this risk of discrimination. *See, e.g.,* Vernellia R. Randall, *Impact of Managed Care Organizations on Ethnic Americans and Under Served Populations*, 5 J. HEALTH CARE FOR THE POOR UNDERSERVED 224 (1994); Vernellia R. Randall, *Managed Care, Utilization Review, and Financial Risk Shifting: Compensating Patients for Health Care Cost Containment Injuries*, 17 U. PUGET SOUND L. REV. 1, 3 (1994).

III. INADEQUACY OF FEDERAL ANTI-DISCRIMINATION PROTECTION

Several federal laws address access to health care: Title XVIII (Medicare)³⁶ and Title XIX (Medicaid)³⁷ of the Social Security Act, Title IX,³⁸ and the Hill Burton Act.³⁹ The only federal law related to eliminating racial discrimination in health care delivery is Title VI of the Civil Rights Act.⁴⁰

Racial inequality in health care persists in the United States despite laws against racial discrimination, in significant part because of the inadequacy of Title VI.⁴¹ On its face, Title VI (with its implementing regulations) should be an effective tool for eliminating racial discrimination. The Civil Rights Act of 1964 provides the legal force for desegregation efforts in health care.⁴² Specifically, Section 601 of Title VI provides: “No person in the United States, shall, on the grounds of race, color, or national origin, be excluded from participation in, be denied the benefits of, or be subject to discrimination under any program or activity receiving federal financial assistance.”⁴³

In short, Title VI appears to prohibit discrimination of all kinds. Still, nothing in anti-discrimination law is as simple as it might appear. While, several problems are that make Title VI and ineffective tool, among the most significant is the interpretation by the Supreme Court that Title VI only addresses intentional discrimination only. Further,

³⁶ Social Security Amendments, Pub. L. No. 89-97, Titles XVIII, 79 Stat. 286 (1965) (the act does not contain any general anti-discrimination clauses although the implementing regulations require providers and facilities to abide by Title VI).

³⁷ *Id.*

³⁸ 20 U.S.C. §§ 1681-88 (2002) (limited to sex discrimination in educational programs).

³⁹ 42 U.S.C. §§ 291a-291(o) (2002) (requires uncompensated care and community service by facilities that receive funding under Hill-Burton Acts).

⁴⁰ *See, e.g.*, DAVID BARTON SMITH, *HEALTH CARE DIVIDED: RACE AND HEALING A NATION* (Univ. of Michigan Press 1999) [hereinafter *HEALTH CARE DIVIDED*]; *see also* David Barton Smith, *Addressing Racial Inequities In Health Care: Civil Rights Monitoring And Report Cards*, 23 J. HEALTH POL. POL'Y & L. 75 (1998); Randall, *Racist Health Care*, *supra* note 25.

⁴¹ *See, e.g.*, Barbara Noah, *Racial Disparities in the Delivery of Health Care?*, 35 SAN DIEGO L. REV. 135 (1998); *see also* Daniel K. Hampton, *Title VI Challenges by Private Parties to the Location of Health Care Facilities: Toward a Just and Effective Action*, 37 B.C. L. REV. 517 (1996); Marianne L. Engelman Lado, *Breaking the Barriers of Access to Health Care: a Discussion of the Role of Civil Rights Litigation and the Relationship Between Burdens of Proof and the Experience of Denial*, 60 BROOK. L. REV. 239 (1994).

⁴² Title VI of the 1964 Civil Rights Act, Pub. L. No. 88-352, 78 Stat. 252 (1964) (codified at 42 U.S.C. § 2000d-2000d-4 (2005)).

⁴³ *Id.*

regulatory agencies have interpreted Title VI to exclude physicians in private practice.

Unfortunately, the Supreme Court has held in *Alexander v. Choate*⁴⁴ that Title VI itself directly reached only instances of intentional discrimination; included in the definition is subtle discrimination. Subtle discrimination⁴⁵ is generally considered intentional based on large part on micro-aggressions⁴⁶ with the primary difference being the reliance on circumstantial evidence to improve intent.⁴⁷ However, the reliance on intent, subtle or direct, is particularly problematic for health care where most discrimination is either disparate impact discrimination or “unthinking or unconscious.”⁴⁸

[T]he course of treatment physicians . . . recommend to their patients may be influenced by stereotypical beliefs about the behavior of their patients. Physicians . . . may believe that poor and minority patients are more likely to break appointments and to misunderstand complex information, and less likely to adhere to their orders. These

⁴⁴ *Alexander v. Choate*, 469 U.S. 287 (1985).

⁴⁵ See, e.g., Terry Smith, *Everyday Indignities: Race, Retaliation and the Promise of Title VII*, 34 COLUM. HUM. RTS. L. REV. 529 (2003); cf. *Lynn v. Regents of Univ. of California*, 656 F.2d 1337, 1343 n.5 (9th Cir. 1981). In *Lynn v. Regents*, the court said: “We are saying only what Title VII commands: when plaintiffs establish that decisions regarding academic employment are motivated by discriminatory attitudes relating to race or sex, or are rooted in concepts which reflect such discriminatory attitudes, however subtly, courts are obligated to afford the relief provided by Title VII.” *Id.*

⁴⁶ See Peggy C. Davis, *Law as Micro-aggression*, 98 YALE L.J. 1559, 1576 (1989).

⁴⁷ See Robert Belton, *Mixed-Motive Cases in Employment Discrimination Law Revisited: A Brief Updated View of the Swamp*, 51 MERCER L. REV. 651, 662-63 (2000) (noting the inability of easily distinguishing direct and circumstantial evidence in the employment discrimination context); cf. Michael Selmi, *Subtle Discrimination: A Matter of Perspective Rather Than Intent*, 34 COLUM. HUM. RTS. L. REV. 657, 667 n.40 (2003) (“The distinction between direct and circumstantial evidence is often a difficult one to make, and in recent years courts have narrowed the range of behavior that is defined as ‘direct evidence’”).

⁴⁸ See, e.g., M. Gregg Bloche, *Race and Discretion in American Medicine*, 1 YALE J. HEALTH POL’Y L. & ETHICS 95, 95-96 (2001) (noting that since 1999 topic of racial bias in American health care has been targeted as topic for research, discussion and intervention by variety of public and private sector initiatives); see also Bowser, *Racial Profiling*, *supra* note 25 (discussing racial bias in medicine and reviewing medical literature demonstrating that African Americans receive lower quality health care than similarly situated white patients); Noah, *Racial Disparities in the Delivery of Health Care*, *supra* note 41 (discussing “racial bias in the delivery of [health] care”); Mary Crossley, *Infected Judgment: Legal Responses to Physician Bias*, 48 VILL. L. REV. 195 (2003).

perceptions may affect—perhaps subconsciously—the decision-making process and lead physicians to refrain from orders that require patient compliance and to hesitate before recommending certain procedure if they assume the patient does not live in an environment that is conducive to the aftercare needed for the best outcomes of the procedure

...⁴⁹

While legal standards for discrimination have not always centered on intent, they do so now.⁵⁰ To prove a disparate treatment claim an individual must show that the defendant intentionally discriminated.⁵¹ Such a standard means that few of the discriminatory acts that occur in the health care system can be successfully litigated since most occur from “unthinking” or “unconscious” biases.

Psychiatric, psychological, and legal literature generally support the idea that, in our society, most contemporary discrimination is based more on unconscious bias and stereotyping rather than on conscious bigotry.⁵² As suggested by Professor Lawrence:

⁴⁹ See, e.g., MARIAN E. GORNICK, *VULNERABLE POPULATIONS AND MEDICARE SERVICES: WHY DO DISPARITIES EXIST?* 43 (Century Found. 2000) (noting that physicians may believe that minority patients are more likely to misunderstand complex information and less likely to adhere to doctor's orders).

⁵⁰ See, e.g., Jessie Allen, *A Possible Remedy for Unthinking Discrimination*, 61 BROOK. L. REV. 1299 (1995) [hereinafter *Unthinking Discrimination*] (arguing that the failure to cover non-motivational forms of discrimination under Title VII “may actually discourage employers ... from acknowledging, let alone actively investigating, the risks of their own unconscious racism,” because “[t]hey receive no credit for doing so and may subject themselves to greater potential liability”).

⁵¹ *Id.*

⁵² Charles Lawrence, *The Id, the Ego, and Equal Protection: Reckoning with Unconscious Racism*, 39 STAN. L. REV. 317 (1987) [hereinafter *Unconscious Racism*]; see also IOM REPORT, *supra* note 2; David B. Oppenheimer, *Negligent Discrimination*, 141 U. PA. L. REV. 899, 967-72 (1993) (setting forth theory of negligent discrimination under Title VII); Sheri Lynn Johnson, *Unconscious Racism and the Criminal Law*, 73 CORNELL L. REV. 1016 (1988). See generally Ann C. McGinley, *Viva La Evolucion!: Recognizing Unconscious Motive in Title VII*, 9 CORNELL J.L. & PUB. POL'Y 415 (2000); Ann C. McGinley, *The Emerging Cronyism Defense and Affirmative Action: A Critical Perspective on the Distinction Between Colorblind and Race Conscious Decision Making Under Title VII*, 39 ARIZ. L. REV. 1003 (1997); *Unthinking Discrimination*, *supra* note 50, at 1299-1304 (asserting that the failure of civil rights laws is related to the reluctance to expand the definition of discrimination to include an objective standard that would address unconscious use of stereotypes); JODY DAVID ARMOUR, *NEGROPHOBIA AND REASONABLE RACISM: THE HIDDEN COSTS OF BEING BLACK IN AMERICA* 68-80 (New York Univ. Press 1997); Paul Brest, *The Supreme Court, 1975 Term-Forward: In Defense of the Antidiscrimination Principle*, 90 HARV. L. REV. 1, 6-7 (1976); Judith

Traditional notions of intent do not reflect the fact that decisions about racial matters are influenced in large part by factors that can be characterized as neither intentional—in the sense that certain outcomes are self-consciously sought—nor unintentional—in the sense that the outcomes are random, fortuitous, and uninfluenced by the decision-maker's beliefs, desires, and wishes.⁵³

The problem confronting the legal system is that an individual who holds a negative stereotype about a group is more likely to discriminate against an individual that fits the stereotype.⁵⁴ This stereotype-linked bias is both an automatic process and an unconscious one.⁵⁵ Furthermore, it occurs even among persons who are not prejudiced.⁵⁶ According to Professor David Williams, several factors contribute to the unbiased discrimination in health care:

First, healthcare providers are a part of the larger society that views racial and ethnic minorities negatively on multiple social dimensions . . . Second, research on

Olans Brown et al., *Some Thoughts About Social Perception and Employment Discrimination Law: A Modest Proposal for Reopening the Judicial Dialogue*, 46 EMORY L.J. 1487, 1493-97 (1997); Martha Chamallas, *The Architecture of Bias: Deep Structures in Tort Law*, 146 U. PA. L. REV. 463, 466-67 (1998); Peggy C. Davis, *Law as Microaggression*, 98 YALE L.J. 1559, 1560 (1989); Barbara J. Flagg, "Was Blind, But Now I See": *White Race Consciousness and the Requirement of Discriminatory Intent*, 91 MICH. L. REV. 953 passim (1993); Sheri Lynn Johnson, *Unconscious Racism and the Criminal Law*, 73 CORNELL L. REV. 1016 passim (1988); Linda Hamilton Krieger, *Civil Rights Perestroika: Intergroup Relations After Affirmative Action*, 86 CAL. L. REV. 1251, 1279, 1286-91 (1998) [hereinafter Krieger I]; Linda Hamilton Krieger, *The Content of Our Categories: A Cognitive Bias Approach to Discrimination and Equal Employment Opportunity*, 47 STAN. L. REV. 1161, 1164 (1995) [hereinafter Krieger II]; Anne C. McGinley, *Rethinking Civil Rights and Employment at Will: Toward a Coherent Discharge Policy*, 57 OHIO ST. L.J. 1443, 1463-73 (1996); David Benjamin Oppenheimer, *Negligent Discrimination*, 141 U. PA. L. REV. 899, 900-17 (1993); Michael Selmi, *Testing for Equality: Merit, Efficiency, and the Affirmative Action Debate*, 42 UCLA L. REV. 1251, 1283-89 (1995); David A. Strauss, *Discriminatory Intent and the Taming of Brown*, 56 U. CHI. L. REV. 935, 960-62 (1989); Pamela S. Karlan, *Discriminatory Purpose and Mens Rea: The Tortured Argument of Invidious Intent*, 93 YALE L.J. 111, 124-28 (1983).

⁵³ *Unconscious Racism*, *supra* note 52 (suggesting that racism is so ingrained that it can be classified neither as intentional nor as unintentional).

⁵⁴ David R. Williams, *Race, Health, And Health Care*, 48 ST. LOUIS U. L.J. 13 (Fall 2003); *see* IOM REPORT, *supra* note 2, at 171-173.

⁵⁵ *Id.*

⁵⁶ *Id.*

stereotypes indicates that encounters in the healthcare setting contain ingredients that enhance the likelihood of the use of stereotypes. Stereotypes are more likely to be activated under conditions of time pressure, the need to make quick judgments, cognitive overload, task complexity and when the emotions of anger or anxiety are present . . . Third, . . . [physicians view their Black patients] . . . more negatively than their white counterparts. . . . Physicians viewed Black patients (compared to their white counterparts) as less likely to adhere to medical advice, less likely to be kind, intelligent and educated, more likely to lack social support, and more likely to abuse alcohol and drugs.⁵⁷

However, notwithstanding that the discrimination is based on some unconscious or unthinking processes, an individual can change⁵⁸:

Social psychological research, reviewed here in four major sections, explains that stereotyping, prejudice, and discrimination have (1) some apparently automatic aspects and (2) some socially pragmatic aspects, both of which tend to sustain them. But, as research also indicates, change is possible, for (3) stereotyping, prejudice, and discrimination seem individually controllable, and consequently, (4) social

⁵⁷ Williams, *Race, Health, And Health Care*, *supra* note 54.

⁵⁸ See, e.g., Susan T. Fiske, *Controlling Other People: The Impact of Power on Stereotyping*, 48 AM. PSYCHOL. 621, 627 (1993) ("Our main program of research . . . has been showing that social structure affects attention, and if people pay more attention, at least some of them are less likely to stereotype"); Susan T. Fiske & Peter Glick, *Ambivalence and Stereotypes Cause Sexual Harassment: A Theory with Implications for Organizational Change*, J. SOC. ISSUES, 1995, at 97, 110-12 (discussing ways in which organizations can decrease the effect of stereotyping); Samuel L. Gaertner et al., *Reducing Intergroup Bias: Elements of Intergroup Cooperation*, 76 J. PERSONALITY & SOC. PSYCHOL. 388, 398 (1999) ("Any intergroup activity that induces the perception of common identity among the groups has the potential to reduce intergroup bias, with or without the components of intergroup cooperative interaction"); Steven L. Neuberg, *The Goal of Forming Accurate Impressions During Social Interactions: Attenuating the Impact of Negative Expectancies*, 56 J. PERSONALITY & SOC. PSYCHOL. 374, 374 (1989) (arguing that having a goal of forming accurate impressions reduces the detrimental impact of negative expectancies); Philip E. Tetlock, *Accountability: A Social Check on the Fundamental Attribution Error*, 48 SOC. PSYCHOL. Q. 227, 233 (1985) (discussing how accountability or requiring people to justify their decisions can result in "debiasing" under certain circumstances).

structure influences their occurrence. . . . The bad news is that people's habitual use of subjectively diagnostic information, certain information configurations, and perceived co-variation sustains stereotypes. . . . The good news is that people can sometimes control even apparently automatic biases, if appropriately motivated, given the right kind of information, and in the right mood. People therefore can make the hard choice.⁵⁹

Recognizing, the need to get at more than intentional discrimination the Office of Civil Rights (OCR) which was delegated the responsibility of enforcing Title VI and Department of Health and Human Services (DHHS) issued interpretive regulations which provided for disparate impact discrimination:⁶⁰

A recipient . . . may not . . . utilize criteria or methods of administration which have the *effect* of subjecting individuals to discrimination of their race, color or national origin, or have the *effect* of defeating or substantially impairing accomplishment of the objectives of the program as respect individuals of a particular race, color, or national origin.⁶¹

The regulations defined a recipient as any public or private entity or individual that receives federal financial assistance.⁶² Federal financial assistance includes federal money awarded through grant, loan, or contract.⁶³ Because of these two definitions, Title VI, had the potential of having a broad range effect. Once a program or individual has been determined to violate Title VI, the program or individual "must take

⁵⁹ Susan T. Fiske, *Stereotyping, Prejudice and Discrimination*, in 2 HANDBOOK ON SOC. PSYCHOL. 357 (Daniel T. Gilbert et al. eds., 4th ed. 1998).

⁶⁰ See H.R. DOC. NO. 318 (1964). See generally Mitchell Rice & Woodrow Jones, Jr., *Public Policy Compliance/Enforcement and Black American Health: Title VI of the Civil Rights Act of 1964*, in HEALTH CARE ISSUES IN BLACK AMERICA: POLICIES, PROBLEMS AND PROSPECTS 100-17 (Woodrow Jones, Jr. & Mitchell F. Rice eds., 1987); Watson, *Reinvigorating Title VI: Defending Health Care Discrimination-it Shouldn't Be So Easy?*, *supra* note 31, at 943-48 (1990).

⁶¹ 45 C.F.R. § 80.3(b)(2) (1991) (emphasis added).

⁶² 45 C.F.R. § 80.3(i) (1991).

⁶³ 42 U.S.C.A. § 2000d-1 (1981); 42 U.S.C.A. § 2000d-4 (1981).

affirmative action to overcome the effects of prior discrimination."⁶⁴ Furthermore, the regulations went further and prohibited:

- Criteria or methods of administration which have the *effect* of subjecting individuals to discrimination;⁶⁵ criteria or methods of administration which have the *effect* of defeating or substantially impairing accomplishment of the objectives of the program;⁶⁶
- Difference in quality of services;⁶⁷
- Differences in quantity or the manner in which the benefit is provided;⁶⁸ and,
- Locating services with the purpose or effect of excluding individuals from the benefits of the program.⁶⁹

In theory then Title VI regulation should improve access to and quality of health care services. Title VI regulations clearly prohibit policies and practices that result in segregation within and between institutions. Title VI's regulations had the potential of forcing health care practitioners and institutions to evaluate their policies and practices that have a disparate impact on racial minorities.⁷⁰ Unfortunately, because of *Alexander v. Sandoval* and unique problems of health care discrimination, Title VI and its regulations are virtually useless.

In *Sandoval*, the court held in a five-to-four decision that despite a line of Title VI precedents, that disparate impact regulation issued under § 602 could only be enforced through a private right of action.⁷¹ Since the law requires a conscious discriminatory purpose or intent, individual discrimination claims cannot address the issue of unconscious discrimination and health care providers will not be "appropriately motivated" to make the hard choice.⁷²

⁶⁴ 45 C.F.R. § 80.3 (b)(6)(i) (1991).

⁶⁵ 45 C.F.R. § 80.3 (b)(1)(vii)(2) (1991).

⁶⁶ 45 C.F.R. § 80.3 (b)(1)(vii)(2) (1991).

⁶⁷ 45 C.F.R. § 80.3 (b)(1)(i) (1991).

⁶⁸ 45 C.F.R. § 80.3 (b)(1)-(3) (1991).

⁶⁹ *Id.*

⁷⁰ In *Alexander v. Choate*, 469 U.S. 287 (1985), the Supreme Court made it clear that a claim seeking a remedy for discrimination based on disparate impact under Title VI must involve a violation of agency regulations promulgated under § 602.

⁷¹ See *Alexander v. Sandoval*, 532 U.S. 275, 280 (2001).

⁷² See, e.g., *Unthinking Discrimination*, *supra* note 50; Interestingly, some members of Congress clearly understand the difference between conscious and unconscious bias. For instance, in its discussion of the American with Disabilities Act (ADA), several members

Even without the problem with Sandoval Title VI enforcement has been problematic⁷³ First, although required by regulation to produce data,⁷⁴ the Office of Civil Right's ("OCR") Title VI enforcement effort has produced little consistent data for evaluating Title VI compliance.⁷⁵ Second, there has been "little uniformity in how different states handle Title VI requirements, little guidance, little analysis of the information collected by this process, no research and development."⁷⁶ Third, Title VI lacks specific definitions of prohibited discrimination and acceptable remedial action.⁷⁷ Fourth, OCR has relied on individual complaints to enforce Title VI.⁷⁸ Finally, Title VI would have limited application to health care treatment discrimination since HEW has interpreted Title VI to not apply to private physicians who received money for treating patients covered under Medicare Part B.⁷⁹ Thus, under Title VI physicians would not be recipients of federal financial assistance and consequently not covered by Title VI.⁸⁰

Taking the "even if" a step further, even if the problems with Title VI enforcement did not exist and Title VI functioned perfectly; the health care industry presents unique problems that would still make Title VI ineffective. Furthermore, the health care system presents several additional problems. First, as with the situation when racial minorities use housing

explained that the ADA was intended to address "institutional, structural, and psychological barriers." 136 CONG. REC. H2599, H2622 (daily ed. May 22, 1990) (statement of Rep. Hoyer); *see also* 135 CONG. REC. S10765, S10802 (daily ed. Sept. 7, 1989) (statement of Sen. Heinz).

⁷³ *See, e.g.,* Watson, *Reinvigorating Title VI: Defending Health Care Discrimination-it Shouldn't Be So Easy?*, *supra* note 31; *Racist Health Care*, *supra* note 25; Lado, *Breaking The Barriers Of Access To Health Care: A Discussion Of The Role Of Civil Rights Litigation And The Relationship Between Burdens Of Proof And The Experience Of Denial*, *supra* note 41; Hampton, *Title VI Challenges By Private Parties To The Location Of Health Care Facilities: Toward A Just And Effective Action*, *supra* note 41.

⁷⁴ 28 C.F.R. § 42.406(a) (1992); 45 C.F.R. § 80.6(b) (1991).

⁷⁵ *See, e.g.,* Sidney Watson, *Health Care in the Inner City: Asking the Right Question*, 71 N.C. L. REV. 1647 (1993).

⁷⁶ *See, e.g.,* Smith, *HEALTH CARE DIVIDED*, *supra* note 40.

⁷⁷ *See, e.g.,* 45 C.F.R. § 80.3(b) (1991); Watson, *Health Care in the Inner City*, *supra* note 75.

⁷⁸ *Id.*

⁷⁹ *Id.*

⁸⁰ *But see* Lesley v. Chie, 250 F.3d 47, 53 (1st Cir. 2001) (discussing physicians' receipt of Medicaid funds in relationship to the Rehabilitation Act.); *Howe v. Hull*, 874 F. Supp. 779, 789 (N.D. Ohio 1994) (discussing physicians' receipt of Medicare and Medicaid funds in relationship to the Rehabilitation Act); However, it is open question whether physicians who receive payment through a managed care plan will be covered.

and lending institutions, individuals are, for the most part, totally unaware that the provider or institution has discriminated against them. Similarly, because of the very specialized knowledge required in medical care, individuals can be totally unaware that the provider has injured them. Finally, the health care system, through managed care, has actually built in incentives that encourage “unconscious” discrimination. Because of these issues, an appropriate legal structure is essential to eliminating discrimination in health care.

IV. STATE HEALTH CARE ANTI-DISCRIMINATION ACT

In an effective public health policy, appropriate state and federal laws must be available to eliminate discriminatory practices in health care. Thus, the crux of the problem, given managed care, the historical inequity in health care, and “unthinking discrimination,” the laws do not address the current barriers faced by minorities. The executive branch, the legislatures and the courts are singularly reluctant to hold health care institutions and providers responsible for institutional racism. As the United States Commission on Civil Rights found:

There is substantial evidence that discrimination in health care delivery, financing and research continues to exist. Such evidence suggests that Federal laws designed to address inequality in health care have not been adequately enforced by federal agencies . . . [Such failure has] . . . resulted in a failure to remove the historical barriers to access to quality health care for women and minorities, which, in turn has perpetuated these barriers.⁸¹

Health Care Anti-Discrimination Act should be enacted which would (1) recognize multiple forms of discrimination (2) authorize and fund testers, (3) assure fines & regulatory enforcement (4) require a health scorecard/report for health agency, provider or facility, and (5) require data collection and reporting.

⁸¹ See, e.g., U.S. COMMISSION ON CIVIL RIGHTS II, *supra* note 4, at 275-276.

A. Recognize Multiple Forms of Discrimination

Racial inequity in medical treatment rarely occurs because of overt, intentional discrimination behavior. Most race discrimination that occurs in health care is probably the result of subconscious bias, disproportionate impact of policies and practices, disparate impact. A state law on health care discrimination would at a minimum define discrimination in a way that included: intentional discrimination, subtle discrimination,⁸² unthinking discrimination⁸³ and disparate impact.⁸⁴ The law should define intentional discrimination to include knowledge of disparate impact and failure to take effective steps to reduce impact. Furthermore, any affirmative defenses, such as business necessity, should be limited and narrowly defined.

B. Authorize and Fund the Use of Medical Testers

To discourage health care discrimination, an 'aggrieved person' should include not only the individual who has been injured, but also one who believes that he or she will be injured, as well as individuals engaged as testers and organizations engaged in testing. In testing, the testing organization sends persons pretending to be patients who share common traits or symptoms except their race to health care facilities or providers to prove that patients of a particular race receive different treatment.⁸⁵ This is

⁸² Subtle discrimination is not necessarily the same as unconscious discrimination. Conscious discrimination can be directed in subtle ways. Michael Selmi, *Response to Professor Wax Discrimination as Accident: Old Whine, New Bottle*, 74 IND. L.J. 1233 (1999); see also ELIZABETH YOUNG-BRUEHL, *THE ANATOMY OF PREJUDICES* 73 (Harvard Univ. Press 1996); Selmi, *Subtle Discrimination: a Matter of Perspective Rather than Intent*, *supra* note 47.

⁸³ See, e.g., *Unthinking Discrimination*, *supra* note 50 (advocating strict liability for unconscious discrimination).

⁸⁴ Cf. Justin D. Cummins, *Refashioning the Disparate Treatment and Disparate Impact Doctrines in Theory and in Practice*, 41 HOW. L. J. 455, 468 (1998) (suggesting that problem is not the requirement of intent but how discriminatory intent is defined and proposing that a more comprehensive intent standard, which includes unconscious bias, be adopted); Amy Wax, *Discrimination as Accident*, 74 IND. L.J. 1129, 1206 (1999) (asserting that the costs of remedying unconscious discrimination are too high for employers to bear, and the victims of discrimination are the "cheapest cost avoiders").

⁸⁵ See, e.g., Stan Dorn et al., *Anti-Discrimination Provisions and Health Care Access*, 20 CLEARINGHOUSE REV. 439, 441, 441 n.27 (1986); *Desnick v. American Broadcasting*, 44 F.3d 1345, 1352 (7th Cir. 1995) (use of test patients with concealed cameras did not support claim for trespass under Illinois law, infringement of right of privacy, or illegal wiretapping).

important because much of health care discrimination goes unnoticed, unsuspected, undetected, or unreported.

Even in cases where discrimination is suspected, the victim will have an almost impossible time developing adequate proof because there will be almost no opportunity to witness better treatment to a similarly situated white patient. "Testing" could provide both evidence in the individual case and some accurate empirical data on the overall rate at which discrimination occurs in health care.⁸⁶ Testing has been widely used to enforce Title VIII,⁸⁷ which prohibits discrimination in the sale, advertising, and rental of housing.⁸⁸ However, while use of tests under Title VIII is well-settled, it is an issue of great debate in other areas, such as employment discrimination under Title VII⁸⁹ and section 1981 of the Civil Rights Act of 1866.⁹⁰ A statute that authorizes the use of testers will bypass that debate in the courts because the Supreme Court has already noted that "Congress may enact statutes creating legal rights, the invasion of which creates standing, although no injury would exist without the statute."⁹¹

⁸⁶ See, e.g., Ian Ayres, *Fair Driving: Gender and Race Discrimination in Retail Car Negotiations*, 104 HARV. L. REV. 817 (1991) (conducting rigorous testing for gender and race discrimination in new-car purchase negotiations and disclosing that women and minorities fare significantly worse in such negotiations than white males); Stephen E. Haydons, *A Measure of Our Progress: Testing for Race Discrimination in Public Accommodations*, 44 UCLA L. REV. 1207 (1997).

⁸⁷ 42 U.S.C. § 3604.

⁸⁸ See, e.g., Haydons, *A Measure of Our Progress: Testing for Race Discrimination in Public Accommodations*, *supra* note 86; *Havens Realty Corp. v. Coleman*, 455 U.S. 363 (1982) (unanimous Court endorsing the use of testers).

⁸⁹ See, e.g., Michael J. Yelnosky, *Filling an Enforcement Void: Using Testers to Uncover and Remedy Discrimination in Hiring for Lower-Skilled, Entry-Level Jobs*, 26 U. MICH. J.L. REFORM 403 (1993) (arguing that Congress should amend Title VII to give the EEOC the power to use testers to uncover discrimination in hiring for lower-skilled, entry-level jobs); Alex S. Navarro, Note, *Bona Fide Damages for Tester Plaintiffs: An Economic Approach to Private Enforcement of the Antidiscrimination Statutes*, 81 GEO. L.J. 2727 (1993) (arguing that testers should receive damage awards comparable to non-tester plaintiffs).

⁹⁰ See, e.g., Michelle Landever, Note, *Tester Standing in Employment Discrimination Cases Under 42 U.S.C. § 1981*, 41 CLEV. ST. L. REV. 381 (1993) (arguing that employment testers have standing to sue under § 1981).

⁹¹ *Linda R.S. v. Richard D.*, 410 U.S. 614, 617 n.3 (1973) (citing *Hardin v. Kentucky Utilities Co.*, 390 U.S. 1, 6, (1968)).

C. Provide a Private and Organizational Right of Action

An anti-discrimination health care statute would provide for a private right of action and organizational right of action. The private right of action would assure that individuals (including testers) would have standing to sue not only under the statute but also under any implementing regulations; thus, avoiding the problem that occurred in federal civil rights enforcement. Furthermore, there are many reasons why limiting enforcement to state agencies may be inadequate. For instance, the agency may not have sufficient staff to devote the resources necessary to enforce the civil rights violations.⁹² Administrative complaints with state agencies rather than going to court may limit some avenues of redress. State agencies may be limited in their capacity to mandate redress for aggrieved plaintiffs.⁹³ Without a private right of action, racial discrimination in health care will be impossible to eliminate.⁹⁴

In addition to the private right of action, an organizational right of action is essential to allowing testing to be carried out more broadly by civil rights organizations. These organizations and testers would have standing to sue and could recoup the costs of testing programs. This would provide the necessary incentive for civil rights organizations to create testing programs and make their existence known to potential victims of discrimination.

D. Establish Equality Health Care Council

The act should establish “Health Care Council,” patterned after Fair housing councils. This council could serve several distinct functions, including educating the public, training health care providers and institutions, providing counseling and health care-finding services to individuals, investigating discrimination complaints—mostly through testing—and pursuing legal remedies.⁹⁵ Such council would provide a focal point, anti-discrimination work in health care.⁹⁶ It could easily be an extension of existing state minority health efforts. Thus, when someone

⁹² See, e.g., Derek Black, *Picking up the Pieces after Alexander V. Sandoval: Resurrecting a Private Cause of Action for Disparate Impact*, 81 N.C. L. REV. 356 (2002).

⁹³ *Id.*

⁹⁴ See *id.*

⁹⁵ See, e.g., Haydons, *A Measure of Our Progress: Testing for Race Discrimination in Public Accommodations*, *supra* note 86.

⁹⁶ See, e.g., *Fair Housing Council Finds Discrimination Against Hispanics in DC*, 66 Number 40 Interpreter Releases 1154 (Oct. 16, 1989).

believes she has been discriminated against in a health care, she would have somewhere to turn for help.

E. Prevailing Party Attorney Fees

The health care anti-discrimination statute would provide for attorneys' fees for a prevailing party.⁹⁷ Many federal statutes authorize attorneys' fees for a prevailing party.⁹⁸ The statute should grant prevailing party status when, because of the law suit, a party's ends are accomplished. Under the catalyst theory, the focus is on whether the party obtained its desired result, despite whether the party obtained a favorable ruling. Prevailing Party Attorney Fees would help to provide the financial incentives needed to pursue.⁹⁹

F. Punitive Damage, in Part or in Whole, to Fund Monitoring and Assessment Programs

Compensatory damages make discrimination victims whole for injuries to their injuries.¹⁰⁰ Punitive damages, on the other hand, punish past conduct, teach defendants not to commit these acts again and deter others from similar behavior.¹⁰¹ Similar to split-recovery statutes,¹⁰² all or

⁹⁷ See, e.g., Macon Dandridge Miller, *Catalysts as Prevailing Parties under the Equal Access to Justice Act*, 69 U. CHI. L. REV. 1347 (2002).

⁹⁸ See, e.g., Civil Rights Act of 1964, Pub. L. No. 88-352, 78 Stat. 259 (codified at 42 U.S.C. § 2000e-5(k) (1994)); Civil Rights Attorney's Fees Awards Act of 1976, Pub. L. No. 94-559, 90 Stat. 2641 (codified at 42 U.S.C. § 1988(b) (1994 & Supp. 2000)); Equal Access to Justice Act, Pub. L. No. 96-481, 94 Stat. 2325 (1980) (codified at 5 U.S.C. § 504, 28 U.S.C. § 2412 (1994 & 1998 Supp.)); 66 Stat. 813 (1952) (codified at 35 U.S.C. § 285 (1994)).

⁹⁹ See, e.g., *Stanton v. Southern Berkshire Regional School District*, 197 F.3d 574, 577 (1st Cir. 1999) (interpreting prevailing party to include catalysts); *Marbley v. Bane*, 57 F.3d 224, 234 (2d Cir. 1995) (recognizing the catalyst theory as a viable form of recovery as a prevailing party); *Baumgartner v. Harrisburg Housing Authority*, 21 F.3d 541, 551 (3d Cir. 1994) (holding that "there is no legal impediment to application of the 'catalyst theory' to show that plaintiffs were 'prevailing parties' notwithstanding the absence of a judgment or consent decree"); *Environmental Defense Fund, Inc. v. EPA*, 716 F.2d 915, 919 (D.C. Cir. 1983) (holding that a party can achieve prevailing party status without having received a final judgment in its favor).

¹⁰⁰ Jason P. Pogorelec, *Under What Circumstances Did Congress Intend to Award Punitive Damages for Victims of Unlawful Intentional Discrimination Under Title VII?*, 40 B.C. L. REV. 1269 (1999).

¹⁰¹ See e.g., *id.*; H.R. REP. NO. 102-40(I) at 64-65 (1991), reprinted in 1991 U.S.S.C.A.N. 549, 602-03.

¹⁰² As of 2003, 12 states had split-recovery statutes. The twelve states are: Alaska,

part of the punitive damages should be placed into a fund that would ultimately be used to promote equality health care including discrimination testing.¹⁰³

G. Require Data Collection and Reporting

Current data collection efforts fail to capture the diversity of racial and ethnic communities in the United States.¹⁰⁴ Data are aggregated information on subgroups within the five racial and ethnic categories that are not collected systematically.¹⁰⁵ Further, racial and ethnic classifications are often limited on surveys and other data collection instruments, and minorities are often misclassified on vital statistics records and other surveys and censuses.¹⁰⁶ To fully understand the health status, of all individuals, as well as to recognize the barriers they face in obtaining quality health care it is important to collect the most complete data on underrepresented groups, and sub-populations.¹⁰⁷ The lack of data on these groups makes it difficult to conduct research studies and comparative analyses.¹⁰⁸ Furthermore, the lack of a uniform data collection method makes obtaining an accurate and specific description of race discrimination in health care difficult. The existing data collection does not allow for regularly collecting race data on provider and institutional behavior.¹⁰⁹

Colorado, Florida, Georgia, Illinois, Indiana, Iowa, Kansas, Missouri, New York, Oregon, and Utah.

¹⁰³ See, e.g., Mathew J. Klaben, *Split-Recovery Statutes: The Interplay of the Takings and Excessive Fines Clauses*, 80 CORNELL L. REV. 104, 105 (1994); Leo M. Stepanian II, Comment, *The Feasibility of Full State Extraction of Punitive Damages Awards*, 32 DUQ. L. REV. 301, 317 (1994).

¹⁰⁴ See, e.g., David R. Williams, *Race/Ethnicity and Socioeconomic Status: Measurement and Methodological Issues*, 26 INT'L J. HEALTH SERVICES 483, 483-505 (1996); Sidney D. Watson, *Race, Ethnicity and Quality of Care: Inequalities and Incentives*, 27 AM. J.L. & MED. 203 (2001).

¹⁰⁵ See, e.g., U.S. COMMISSION ON CIVIL RIGHTS I, *supra* note 2, at 50-52.

¹⁰⁶ See, e.g., Williams, *Race/Ethnicity and Socioeconomic Status: Measurement and Methodological Issues*, *supra* note 104.

¹⁰⁷ See, e.g., U.S. COMMISSION ON CIVIL RIGHTS I, *supra* note 2, at 50-52.

¹⁰⁸ Williams, *Race/Ethnicity and Socioeconomic Status: Measurement and Methodological Issues*, *supra* note 104.

¹⁰⁹ See *Madison-Hughes v. Shalala*, 80 F.3d 1121, 1123 (6th Cir. 1996) (dismissing for lack of subject matter jurisdiction); U.S. COMMISSION ON CIVIL RIGHTS, FEDERAL TITLE VI ENFORCEMENT TO ENSURE NONDISCRIMINATION IN FEDERALLY ASSISTED PROGRAMS 246 (1996); Lado, *Unfinished Agenda: the Need for Civil Rights Litigation to Address Race Discrimination and Inequalities in Health Care Delivery*, *supra* note 25.

Given the array of potential issues, some researchers have argued that health data should not be disaggregated by race.¹¹⁰ It could be argued that the use of race in health data promotes and maintains the view that race is a biological concept or that racial categorizations perpetuate and encourage racial fragmentation. Such views see potential for harm from the use of race.

However, there are a number of important and compelling reasons for disaggregating health status and health care data by race. First, the use of race is not the cause of racism but the result of racism. That is, individuals have been discriminated against based on color; established hierarchy and superiority are based on color. Consequently, racism and racial discrimination will continue to exist (that is, discrimination based on color) even if terminology change or cease to exist. For instance, even though race data are not collected in the European Union in the same way as they are in the United States, racism and racial discrimination continues to exist as a worldwide problem. Here in the United States, even when one controls for socioeconomic status, health status and health care differentials continue to exist.

Second, racism and racial discrimination have implications for every institution and social practice. Health status is impacted by racial discrimination in housing, employment, environment, education, and other institutions. Third, calls to not disaggregate data ignore the power and status differentials that exist among all racial groups.¹¹¹ This point is illustrated when one considers the disproportionate percentage of racially disadvantaged individuals who are poor. Fourth, as long as some groups continue to experience discrimination, it is important to monitor their well being.¹¹² Fifth, to fully understand the health status of all individuals as well as to recognize the barriers they face in obtaining quality health care, it is important to collect the most complete data on "racially disadvantaged" groups and "sub-groups".¹¹³ The lack of a uniform data collection method makes obtaining an accurate and specific description of racial discrimination in health care difficult, if not impossible. Such data collection has to include collecting data on provider and institutional behavior.

¹¹⁰ C. Bagley, *A Plea for Ignoring Race and Including Insured Status in American Research Reports on Social Science and Medicine*, 40 SOC. SCI. MED. 1017, 1017-19 (1995).

¹¹¹ Williams, *Race, Health and Health Care*, *supra* note 54, at 322-333.

¹¹² *Id.*

¹¹³ Randall, *Racist Health Care*, *supra* note 25, at 127-194.

“Although not useful as a biological category, race has been and is likely to continue to be an important social category. It is what sociologists call a master status—a central determinant of social identity and obligations, as well as of access to societal rewards and resources. From our earliest health records, race has been an empirically robust predictor of variations in morbidity and mortality. Collecting the appropriate data on race can facilitate ongoing monitoring of the magnitude of differentials, enhanced understanding of their causes and the development of effective interventions to address them.”¹¹⁴

Race matters because racism and racial discrimination matter.¹¹⁵ Disaggregating data based on race is important because it helps to make the impact of racism and racial discrimination visible and thus allows us to address the root problem.

H. Require a Health Report Card for Health Agency, Provider or Facility¹¹⁶

If we are serious about eliminating racial discrimination, the systematic collection and reporting of data from each health care provider on racial inequities in the use of services and the choices of diagnostic and therapeutic alternatives would provide an additional tool in civil rights monitoring.¹¹⁷ The “report card” approach is not new and is being done to “assure accountability, consumer choice, and goal-directed action.”¹¹⁸ Existing and proposed health care “report cards” could be used and only need to be stratified by race.¹¹⁹ As Sidney Watson discussed:

¹¹⁴ Williams, *Race, Health and Health Care*, *supra* note 54, at 322-333.

¹¹⁵ JAMES M. JONES, *PREJUDICE AND RACISM* 352-356 (McGraw-Hill 1997).

¹¹⁶ See, e.g., Smith, *Addressing Racial Inequities in Health Care: Civil Rights Monitoring and Report Cards*, *supra* note 40.

¹¹⁷ Smith, *HEALTH CARE DIVIDED*, *supra* note 40, at 325; H. Jack Geiger, *Race and Health Care—An American Dilemma*, 335 *NEW ENG. J. MED.* 815, 816 (1996); Bowser, *Racial Profiling*, *supra* note 25.

¹¹⁸ See Smith, *Addressing Racial Inequities in Health Care: Civil Rights Monitoring and Report Cards*, *supra* note 40.

¹¹⁹ See, e.g., Smith, *HEALTH CARE DIVIDED*, *supra* note 40, at 326; NAT'L COMM. QUALITY ASSURANCE, *HEALTH PLAN AND EMPLOYER DATA INFORMATION SET* (version 3.0 1998); Alain C. Enthoven & Carol B. Vorhaus, *A Vision of Quality In Health Care Delivery*, *HEALTH AFFAIRS* (May/June 1997); Bowser, *Racial Profiling*, *supra* note 25.

Reporting race-based data on health care is relatively easy once we get over our squeamishness about talking about race and recognize the need for this information. Physicians already gather information on patient race as part of a standard medical history. All this is needed is to compile and report racial and ethnic information in a format that protects patient confidentiality and privacy. . .¹²⁰

Report cards that reflect racial disparities will provide a strong evidence that racism, “intentional or unintentional, institutional or individual—is affecting patient care.”¹²¹

I. Assure Adequate Fines and Regulatory Enforcement

The importance of rigorous enforcement of regulation as a primary vehicle for policing health services cannot be overemphasized. The collection of data and the development of a report card need the teeth of regulatory enforcement. Thus, a statute which allows significant civil penalty to be assessed for violation of regulations designed to eliminate racial inequities is important to compliance. Current administrative penalty involves termination of funds. Such a step is highly unlikely; consequently, it is the effective equivalent of having no penalty at all. If substantial fines were mandated and collected for violating anti-discrimination law, then such fines could be collected and deposited directly into a restricted account that could be used only to enhance and improve racial inequities.

V. Conclusion

The questions raised are: why modifying existing federal law (i.e., Title VI) is insufficient or why not adopt a Health Care Anti-Discrimination Law on the federal level? My discussion above should answer the first question. Title VI is hopelessly flawed and minor tinkering will not be sufficient to make it an effective tool. As to the question of why not a new federal law, frankly the answer is political feasibility. From a political perspective, the antagonism to civil rights makes it highly unlikely such an approach will work. Furthermore, the

¹²⁰ See, e.g., Sidney D. Watson, *David Barton Smith's Health Care Divided: Race and Healing a Nation*, 21 J. LEGAL MED. 601 (2000) (book review).

¹²¹ *Id.*

states are major players in the civil rights arena and have an infrastructure on which a new civil rights law could be based.

The discussion of discrimination in health care has been limited. That discussion has centered almost entirely around Title VI of the Civil Rights Act¹²² and on assuring access to facilities and providers.¹²³ In an effective public health policy, appropriate state and federal laws must be available to eliminate discriminatory practices in health care. Thus, the crux of the problem for the legal system: given managed care, the historical inequity in health care, and unthinking discrimination, what is the best way for the legal system to remedy racial discrimination in the health care system?

¹²² See, e.g., Watson, *Reinvigorating Title VI: Defending Health Care Discrimination--it Shouldn't Be So Easy?*, *supra* note 31; Smith, HEALTH CARE DIVIDED, *supra* note 40; Smith, ADDRESSING RACIAL INEQUITIES IN HEALTH CARE: CIVIL RIGHTS MONITORING AND REPORT CARDS, *supra* note 40; Randall, *Racist Health Care*, *supra* note 25.

¹²³ See, e.g., Noah, *Racial Disparities*, *supra* note 41; Hampton, *Title VI Challenges By Private Parties To The Location Of Health Care Facilities: Toward A Just And Effective Action*, *supra* note 41; Barbara A. Noah, *Racist Health Care?*, 35 SAN DIEGO L. REV. 135 (1998); Lado, *Breaking The Barriers Of Access To Health Care: A Discussion Of The Role Of Civil Rights Litigation And The Relationship Between Burdens Of Proof And The Experience Of Denial*, *supra* note 41.

AN EXAMINATION OF VARIANCE IN RISK FACTORS ASSOCIATED WITH DIAGNOSIS OF CORONARY HEART DISEASE

Terry L. Mills, Ph.D.¹

I. ABSTRACT

Risk factors associated with coronary heart disease (CHD) are well-established in the literature. Still, there is a need for continuing investigation into variance in the clustering and effect of these risks across racial/ethnic and gender categories. This study examined differences in the odds of diagnosed CHD in the United States, among black and white men aged 45 and over, and women aged 55 and over. Annually in the U.S., more than 30 percent of all black deaths result from cardiovascular disease. Yet the rate of this illness and related death varies across racial groups. Nonetheless, given the persisting disparity in CHD-related morbidity and mortality, research has not adequately addressed whether there are different constellations of CHD risk factors that are more or less evident in different demographic groups. Using data from the 2002 National Health Interview Survey, with a national probability sample of adults, descriptive statistics support previous reports of a disproportionate percentage of U.S. blacks with multiple risk factors for CHD. However, logistic regression models reveal different combinations of independent risk factors associated with CHD diagnosis for blacks and whites, and also specific gender distinctions associated with the odds of having a diagnosis of CHD. Eliminating disparities among diverse population groups requires aggressive efforts focused on specific demographic group risk assessment, guideline adherence, and risk factor control.

KEY WORDS: Health disparities, coronary heart disease, ethnicity and health, African American health status.

¹ Address correspondence to Terry L. Mills, Ph.D. Associate Professor of Sociology, and Associate Dean for Minority Affairs. University of Florida, 200 Walker Hall, Gainesville, FL 32611-8005. (352) 392-0786, email: tlmills@ufl.edu.

II. INTRODUCTION

Although in the United States death rates due to CHD have declined, the disparity between African Americans and whites has increased. For example, data indicate that CHD death rates declined by 33.3 percent in African-American men between 1979 and 1998, compared to 46.1 percent in white men. At the same time, CHD death rates decreased by 26.6 percent in African American women compared to 40.1 percent in white women (American Heart Association 2002; World Health Organization n.d.). Even with this decline in mortality related to CHD, recent data show that each year, nearly 37 percent of all African American deaths are due to CHD (American Heart Association 2005). The risk factors for CHD have been well-documented in the literature, and include lifestyle and medical conditions, such as dyslipidemia (disorders of lipoprotein metabolism related to high serum cholesterol) (Alderman et al. 1994; Kannel 1996; Lamarche 2002), major depression (Katon et al. 2004), cigarette smoking (Ebbert et al. 2004; Henley et al. 2004), high blood pressure (Grundy et al. 1999), alcohol abuse (Ebbert et al. 2004), physical inactivity (Snell & Mitchell 1999), diabetes mellitus (Summerson et al. 1996), and obesity (Jousilahti et al. 1996; Nelson, et al. 2002). Metabolic syndrome, a related condition, also confers a high risk for CHD, as well as for the development of type 2 diabetes (Haffner 2002; Kahn & Valdez 2003). Diabetes and metabolic syndrome are characterized by the presence of central obesity and insulin resistance, which result in dyslipidemia, hypertension, and cardiovascular derangements that promote CHD.

In spite of having a higher CHD risk, black men and women in the U.S. are less likely to receive adequate treatment or control risk factors. Eliminating disparities among population groups will thus require aggressive efforts focused on specific demographic group risk assessment, guideline adherence, and risk factor control among populations in need.

This study investigated variance in the likelihood of physician diagnosed CHD among black and white adults in the U.S. To achieve this aim, the investigator focused on men aged 45 and over, and women aged 55 and over. Emphasis was placed on these two age cohorts, since previous empirical evidence has suggested that, in general, the incidence of CHD is low in men and women under age 35 years. Although men are more likely to develop the symptoms of CHD after they have passed the age of 45, women have a ten-year "reprieve," and seem to be protected

from CHD by the effects of estrogen until post menopause, which normally occurs in the mid-50s (Snell & Mitchell 1999; Zagaria n.d).

III. BACKGROUND

Recent studies of black and white women with CHD indicate that the risk for cardiovascular mortality was higher among black women than white women, and the reasons for this disparity are largely unexplored (Jha et al. 2003). Despite the differences in mortality due to heart disease, in their study, Jha indicated that black women less often received appropriate preventive therapy and adequate risk factor control despite a greater CHD event risk. Other researchers also have investigated racial/ethnic differences in cardiovascular disease (CVD) mortality (Jones-Webb et al. 2004). In their study, Jones-Webb reported that older black men who lived in more impoverished neighborhoods had significantly and disproportionately higher CVD mortality rates than did older white men living in more impoverished neighborhoods. However, this was not the case among older black and white men living in less impoverished neighborhoods. The study concluded that socioeconomic status as measured by neighborhood poverty moderates the effects of race on CVD mortality in older black and white men. Further, the researchers postulated that this effect may not have been as apparent without the inclusion of socioeconomic position as a major variable of interest, and the measurement of it at multiple levels.

A within-group study of hypertension among black women and men ranging in age from 20-80 (Collins & Winkleby 2002) identified distinct subgroups with highly variable rates of hypertension (11-78 percent). The two groups with the highest rates of hypertension were more likely to be middle-aged or older, less educated, overweight or obese, physically inactive, and have diabetes. The two groups with the lowest hypertension rates were more likely to be younger, but were also overweight or obese. Among hypertensives, those who were uncontrolled and not on antihypertensive medications were male, younger age, and had infrequent contact with a physician. These investigators have pointed to the importance of recognizing that hypertension rates vary substantially within African Americans, and they also highlight the need for effective weight management, diabetes control, and increased access to health care for those at highest risk.

In an examination of the relationship between alcohol consumption and risk for CHD (Fuchs et al. 2001), it was reported that blood pressure was higher in black men who consumed low to moderate amounts of

alcohol compared with non-consumers. Overall, the consumption of alcohol in amounts greater than or equal to 210 grams per week (roughly 7.5 ounces) was an independent risk factor. Still, the consumption of low to moderate amounts of alcohol also appears to be associated with a higher risk of hypertension in black men. Although a highly correlated relationship is documented in the literature, it remains unclear whether there is some consumption threshold.

Research examining the link between major depression and cardiac risk among patients with diabetes mellitus found that patients with major depression and diabetes were between 1.5 and two times more likely to have three or more cardiovascular risk factors, compared with patients with diabetes, but without depression (Katon et al. 2004). The investigators recommended that interventions aimed at decreasing these risk factors may need to address treatment for major depression in order to be effective. Another study (Berkman et al. 2003) investigating the effects of depression and low perceived social support (LPSS) after myocardial infarction indicates that depression and low perceived social support was associated with higher morbidity and mortality. However, there is a dearth of empirical literature addressing whether this excess risk is reduced through treatment. The objective of the Berkman study was to determine whether mortality and recurrent infarction was reduced by treatment of depression and low perceived social support with cognitive behavior therapy. The findings showed that intervention improved depression and social isolation, although the relative improvement in the psychosocial intervention group compared with the usual care group was less than expected due to substantial improvement in usual care patients.

Examinations of the relationship between family history measures, and the risk for CHD considered family size (American Heart Association 2004), and the incidence of myocardial infarction (MI). A study by Vitullo (1996) illustrated that large family size seemed to be protective for MI. On the other hand, a 1999 study by Silberberg and reported that some risk factors for CHD increased with family size.

Given the identified risks factors for CHD and suggested protective influences, as outlined above, the present investigation was interested in three specific research questions, as indicated below:

1. What is the distribution of physician diagnosed CHD among black and white U.S. males aged 45 and over, and females aged 55 and over?
2. Are there significant racial/ethnic, or gender differences in the risk factors associated with diagnosed CHD?

3. What factors account for the racial/ethnic and gender variance in the odds of having a diagnosis of CHD?

IV. METHOD

Data are from the 2002 National Health Interview Survey² (National Center for Health Statistics 2003) with a probability sample of 31,044 adults aged 18 and over. All analyses used weight factor to construct U.S. population estimates from this probability sample. Descriptive statistics and logistic regression models were used to analyze males age 45 and over, and females age 55 and over. Therefore, the population estimates of this analytic sample are white males (N = 25,505,035), black males (N = 2,684,180), white females (N = 16,413,968), and black females (N = 1,807,513). The dependent variable was a binary measure of whether a physician had diagnosed the individual as having CHD (0 = no, 1 = yes). Independent and control variables included a continuous measure of chronological age (black men M = 57.9, SD = 10.47), (white men M = 60.1, SD = 11.28), (black women M = 66.9, SD = 9.0), (white women M = 68.5, SD = 9.4), education level by category (on average, slightly more than high school education), marital status (0 = never married, 1 = previously married, 2 = married), a binary measure of ratio of income to poverty level (at or below poverty level = 0; above poverty level = 1), and several physician diagnosed or self-reported CHD risk factors including, high cholesterol (0 = no, 1 = yes), hypertension (0 = no, 1 = yes), diabetes (0 = no, 1 = yes), obesity (BMI 30+ = yes), overweight (BMI 25.0-29.9 = yes), smoking status (0 = never smoked, 1 = former smoker, 2 = current smoker), alcohol use (0 = lifetime abstainer; 1 = former drinker, no drinks in past 12 months, 2 = current drinker).

Additionally, this study controlled for whether the respondent had a usual place for health care (0 = no, 1 = yes), use of health facility at least ten times per year (0 = no, 1 = yes), functional limitations (e.g., difficulties bathing, walking a distance, toileting, etc.), self-reported depressive symptoms (sad, nervous, restless, hopeless, effort, worthless). For each of the depressive symptoms the respondents were asked how frequently they experienced the symptoms during the past 30 days (0 = none of the time, 1 = little of the time, 2 = some of the time, 3 = most of

² Disclaimer – all analyses, interpretations, or conclusions reached in this study are credited exclusively to the author (recipient of the data file) and not to NCHS, which is responsible only for the initial data.

the time, 4 = all the time). The index of the six depressive symptoms yielded an alpha coefficient of 0.877. The range of the depression index was from 0-24 with higher scores indicating more frequency of collective symptoms of depression. In this sample, the mean depressive score for black men was 1.82 (SD = 3.44), compared to their white counterparts (M = 1.88, SD = 3.53). Alternatively, among the females in this study, the level of depression for black women was on average 2.27 (SD = 3.70), compared to white women (M = 2.31, SD = 3.79). In general then, both male groups reported depression a "little of the time." On the other hand, as would be expected, both groups of women reported greater frequency of depressive symptoms, which on average was typically "some or most of the time."

V. RESULTS

A. Descriptive Analyses

The data show that 6.1 percent of black men age 45 and older reported a physician's diagnosis of CHD, compared with 11.6 percent of white men the same age. Among the women in this study, 7.9 percent of black women aged 55 and over, compared with 8.5 percent of white women in the same age cohort reported physician diagnosed CHD. In terms of high cholesterol levels, the distribution of this risk factor was about 28 percent of black men, contrasted with 36.5 percent of white men. Conversely, a similar proportion of black women (39.8 percent) and white women (39.5 percent) reported high cholesterol levels. As expected, there was a statistically significant ($P < .001$) greater proportion of black men with doctor diagnosed hypertension (48 percent), compared to 39 percent of white men in the same age cohort. As with the prevalence of hypertension among the black men in this study, there also was a statistically significant ($P < .001$) greater proportion of black women (65 percent), compared to white women (48 percent) who reported physician diagnosed hypertension. Nearly 6 percent (5.9 percent) of black men reported diagnosis of stroke, versus 4.7 percent of white men. Among the women in this study, there was a comparable proportion with diagnosis of stroke. For example, 6.5 percent of black women, and 6.1 percent of white women reported having a diagnoses of stroke. In considering the distribution of diabetes, black men (16.2 percent) were significantly more likely ($P = 0.03$) to report a diagnosis of diabetes than white men (13.3 percent). Not surprisingly, black women (24.3 percent) also were significantly more likely ($P < .001$) to have a diagnosis of diabetes than their white counterparts (12.7 percent).

A major concern regarding risk for CHD is being overweight and /or obese. Although obesity has of late been receiving more media attention, the proportion of individuals in the U.S. who are overweight and/or obese is staggering. This is particularly alarming among the African American population. To illustrate, the data show that 48.5 percent of black women aged 55 and over are obese ($M_{\text{BMI}} = 34.12$, $SD = 17.84$), versus 27.6 percent of white women ($M_{\text{BMI}} = 29.43$; $SD = 12.23$) in the same age cohort. If you also consider the proportion of black women in this age cohort that are overweight (34.9 percent), the combined percentage of these women who are either obese or overweight is more than 80 percent. Unfortunately, the picture among black men aged 45 and

over is equally disturbing. Specifically, 50.0 percent of black men age 45 and over, in this study, versus 53.2 percent of white men in the same age group, are overweight. Further, 31.4 percent of black men aged 45 and over are obese ($M_{\text{BMI}} = 29.64$, $SD = 12.61$), compared with 27.7 percent of white men in the same age group ($M_{\text{BMI}} = 29.43$, $SD = 12.23$). As with the black women in this study, more than 80 percent of black men aged 45 and over are either overweight or obese.

B. Multivariate Logistic Regression Analysis

Tables 1-4 illustrate the odds ratios associated with each independent risk factor regressed on physician diagnosed CHD. *Statistically significant odds ratios are indicated in bold print.* For each logistic regression model, the complete set of independent and control variables were entered at the same time. A goal of this study was to identify sources of variance in risk factors related to the chance of having a diagnosis of CHD. As shown in Tables 1-4, there were different sets of risk factors linked with the odds of having physician diagnosed CHD. For example, in Table 1, the data show that for black males the odds of having CHD are increased with advancing age (5 percent increase in risk with each year), having diabetes (more than three times increased risk, compared with those not having diabetes), and hypertension (nearly four times increased risk, compared with those not having hypertension).

By comparison, in Table 2, the logistic regression model points to a larger and somewhat different set of risk factors for white males. In this case, advancing age had a comparable risk effect as that for black men. However, also shown is that for white men, several significant factors emerged that were not significant for black men. These included being married (increased the chance of diagnosis for CHD by 39 percent, compared to unmarried white men), smoking habits (smokers had 12 percent greater odds than non-smokers or former smokers), high cholesterol (more than 4.5 times the chance of CHD diagnosis than those white men without high cholesterol), diabetes (more than 2 times the chance of CHD diagnosis, compared with white men not having diabetes), hypertension (about 38 percent greater odds of CHD diagnosis), health facility use (nearly 65 percent increased chance of CHD diagnosis), and functional limitations (about 70 percent increase in the odds of having CHD diagnosis, compared with less physically active counterparts).

In Table 3 and Table 4, the data for women also illustrate specific race and gender distinctions in the cluster of CHD risk factors. For example, Table 3 shows that unlike black men, for black women, having

high cholesterol was a significant risk factor that more than doubled their odds a CHD diagnosis. Additionally, for black women, having diabetes more than doubled the chances of CHD. Further, black women who used health facilities had more than four times the likelihood of a physician diagnosis of CHD. An important result is the relationship between frequency of depressive symptoms and CHD. Among the black women in this study, those with frequent depressive symptoms had 14 percent greater chance of having CHD.

Looking at the results for white women, the data reveal that similar to white men, there is a larger constellation of risk factors when compared to their black female counterparts. Specifically, among white women, advancing age (5 percent more likely with each year), family size (22 percent increase in chance for CHD diagnosis with each additional family member), smoking status (18 percent more likely CHD diagnosis than non-smokers), high cholesterol (nearly a three times greater risk when a white woman has high cholesterol), and diabetes (nearly 63 percent increased likelihood of CHD diagnosis) were each identified as risk factors. Moreover, for white women, hypertension was found to be significantly to CHD diagnosis with more than two times increased odds of CHD diagnosis. Unlike black women, white women having functional limitations was a significant factor that tripled the risk of having diagnosis of CHD. Further, the chances of having diagnosed CHD increased by 3 percent as the frequency of depressive symptoms also increased.

**TABLE 1- Odds of Diagnosis of CHD Among U.S. Black Males
Age 45 and Over Pseudo R2 = .22**

Coronary Heart Disease	Odds Ratio	Std. Err.	T	P > t	[95% Conf.	Interval]
Age	1.054174	.02297	2.42	0.015	1.010099	1.100172
Education	1.081674	.0868001	0.98	0.328	.9242454	1.265918
Marital Status	2.241965	1.239739	1.46	0.144	.7584289	6.627393
Family Size	.8080154	.2180839	-0.79	0.430	.4760664	1.371424
Above Poverty Level	1.370395	.8113716	0.53	0.595	.4293846	4.373658
Obese	.4145551	.266872	-1.37	0.171	.1173782	1.464121
Overweight	.5626993	.2719064	-1.19	0.234	.2182421	1.450822
Smoking Status	1.375434	.3284026	1.34	0.182	.8613779	2.196272
Alcohol Use	1.113089	.4636689	0.26	0.797	.4919647	2.518406
High Cholesterol	1.449252	.8033259	0.67	0.503	.4889839	4.2953
Diabetes	3.095784	1.728486	2.02	0.043	1.036309	9.248092
Hypertension	3.784661	2.285051	2.20	0.028	1.158971	12.35895
Health Facility Use	.1621119	.2135145	-1.38	0.167	.0122646	2.142775
Functional Limitations	1.941875	.9596775	1.34	0.179	.7371122	5.115745
Depressive Symptoms	1.065155	.0578401	1.16	0.245	.9576095	1.184779

Data Source: National Center for Health Statistics (2002)

TABLE 2 - Odds of Diagnosis of CHD Among U.S. White Males Age 45 and Over Pseudo R2 = .21

Coronary Heart Disease	Odds Ratio	Std. Err.	t	P > t	[95% Conf.	Interval]
Age	1.064454	.0072604	9.16	0.000	1.050318	1.078781
Education	.9859201	.0226796	-0.62	0.538	.9424537	1.031391
Marital Status	1.395115	.187324	2.48	0.013	1.07229	1.815132
Family Size	.8936383	.0782667	-1.28	0.199	.7526756	1.061001
Above Poverty Level	1.279346	.3362799	0.94	0.349	.7642494	2.141612
Obese	1.17107	.2418162	0.76	0.444	.7812809	1.755328
Overweight	1.172113	.2154793	0.86	0.388	.817481	1.680588
Smoking Status	1.123936	.0761856	1.72	0.085	.9841024	1.28364
Alcohol Use	.9122118	.0902788	-0.93	0.353	.7513641	1.107493
High Cholesterol	4.783097	.6522078	11.48	0.000	3.661304	6.248597
Diabetes	2.225001	.3669569	4.85	0.000	1.610419	3.074126
Hypertension	1.377987	.1904138	2.32	0.020	1.051036	1.806644
Usual Place for Health Care	1.288127	.5357615	0.61	0.543	.5700406	2.910797
Health Facility Use	1.644238	.3190008	2.56	0.010	1.124122	2.405007
Functional Limitations	1.692109	.2480335	3.59	0.000	1.269552	2.25531
Depressive Symptoms	1.014457	.0162503	0.90	0.370	.9831004	1.046814

Data Source: National Center for Health Statistics (2002)

TABLE 3 - Odds of Diagnosis of CHD Among U.S. Black Women Age 55 and Over Pseudo R2 = .21

Coronary Heart Disease	Odds Ratio	Std. Err.	t	P>t	[95% Conf.	Interval]
Age	1.085212	.0293752	3.02	0.003	1.029136	1.144344
Education	1.003811	.0575593	0.07	0.947	.8970995	1.123215
Marital Status	.9054414	.4228889	-0.21	0.832	.3624791	2.261714
Family Size	1.091168	.153745	0.62	0.536	.8278493	1.438242
Above Poverty	.9628639	.3941794	-0.09	0.926	.431598	2.148079
Obese	1.140897	.7359875	0.20	0.838	.3221891	4.040006
Overweight	.485257	.3084267	-1.14	0.255	.1396124	1.68663
Smoking Status	1.356419	.2882787	1.43	0.151	.8942911	2.057353
Alcohol Use	.9821307	.2474966	-0.07	0.943	.5993152	1.609472
High Cholesterol	2.62467	1.09178	2.32	0.020	1.161402	5.931529
Diabetes	2.762534	1.207931	2.32	0.020	1.172454	6.509077
Hypertension	2.053024	1.501247	0.98	0.325	.4897005	8.607112
Health Facility Use	4.33455	3.810987	1.67	0.095	.7736019	24.28681
Functional Limitations	2.590007	1.689342	1.46	0.145	.7212268	9.301009
Depressive Symptoms	1.143626	.0581861	2.64	0.008	1.035079	1.263555

Data Source: National Center for Health Statistics (2002)

TABLE 4 - Odds of Diagnosis of CHD Among U.S. White Women Age 55 and Over Pseudo R2 = .16

Coronary Heart Disease	Odds Ratio	Std. Err.	t	P>t	[95% Conf.	Interval]
Age	1.05117	.0099762	5.26	0.000	1.031797	1.070907
Education	.9858194	.0291193	-0.48	0.629	.9303644	1.04458
Marital Status	.9508896	.1559158	-0.31	0.759	.689529	1.311317
Family Size	1.221799	.1434764	1.71	0.088	.9705939	1.53802
Above Poverty Level	1.365977	.278999	1.53	0.127	.9153291	2.038494
Obese	.8606599	.1772894	-0.73	0.466	.5747529	1.28879
Overweight	.8641194	.1647908	-0.77	0.444	.5946177	1.255769
Smoking Status	1.184329	.0860955	2.33	0.020	1.027047	1.365697
Alcohol Status	.9208223	.0921888	-0.82	0.410	.7567503	1.120467
High Cholesterol	2.650971	.4282438	6.04	0.000	1.93149	3.638457
Diabetes	1.629893	.3036858	2.62	0.009	1.131235	2.348365
Hypertension	2.140032	.3758031	4.33	0.000	1.516826	3.019288
Usual Place for Health Care	1.935695	1.091369	1.17	0.241	.6410516	5.84495
Health Facility Use	.967081	.2780988	-0.12	0.907	.5503942	1.699229
Functional Limitations	3.141075	.7247156	4.96	0.000	1.998374	4.93719
Depressive Symptoms	1.03261	.0160827	2.06	0.039	1.001563	1.064619

Data Source: National Center for Health Statistics (2002)

VI. DISCUSSION

This study was interested in identifying differences in the distribution of physician diagnosed CHD, and associated risk factors among black and white U.S. males aged 45 and over, and females who were over 55 years of age. A particular emphasis of this study was racial/ethnic and gender variance in the chance of having a diagnosis of CHD. The findings provide preliminary support for placing the probability of physician diagnosed CHD into a more specific context of race/ethnicity and gender. As reported earlier in this paper, the data suggested distinct sets of significant risk factors with varying effects on the likelihood of CHD diagnosis for black men and women, compared with white men and women. Of course, in the broader context of risk factors associated with CHD, this study is not attempting to minimize or negate the empirically established links to CHD. Rather, the findings of this study magnify the importance of specialized public health education and intervention strategies for specific risk control. Nonetheless, it is important to use caution when interpreting the findings of the present study for several circumstances.

First, the outcome of interest here was physician diagnosed CHD, or the prevalence of doctor-diagnosed CHD. This outcome is different from “prevalence” of CHD in the epidemiological sense (e.g., the ratio for a given time period, of the number of occurrences of a disease or event to the number of units at risk in the population). The findings indicated that in general, white males were more likely than black males to have had a diagnosis of CHD. From these data, it should *not* be concluded that the prevalence of CHD is lower among black men. Rather, the smaller proportion of black men reporting a physician's diagnosis of CHD may be due to less frequent physician visits, less access to health care, or physician bias. To illustrate, about 20 percent of black Americans lack a usual source of health care, and 16 percent of African Americans rely on clinics and hospitals for their usual health care (Blendon et al. 1989; Weissman et al. 1991; AHRQ 2000; Adamson et al. 2003). Indeed, prior studies have suggested that blacks may be more likely than whites to delay seeking care for CHD symptoms (Frayne et al. 2002). A related explanation may come from the observation that blacks less often receive appropriate preventive therapy and adequate risk factor control (Jha et al. 2003).

A second point of caution about the findings of this study is in the interpretation of the non-significance of risk factors such as obesity, being

overweight, smoking patterns, or alcohol use among blacks. Although the independent effects of these particular risk factors were not statistically significant for black men and women, in a separate analysis not reported here, as would be expected, obesity was significantly correlated with high cholesterol, hypertension, and diabetes. Obviously, these findings of non-significance do not suggest that black women and men are to be less concerned about their BMI, and other health or lifestyle statuses.

Although there were few, if any surprises revealed by these data analyses, the findings do draw attention to important racial/ethnic and gender differences in the prospect of having a physician's diagnosis of CHD. For example, the finding that white men with diabetes had less likelihood of CHD diagnosis than black men with diabetes may indicate better illness control and treatment of diabetes for white men (Jha et al. 2003). Another explanation, although contrary to the "better/less adequate care hypotheses" is that these results are consistent with the concept that racial differences in risk are a result of differential genetic susceptibility to the adverse effects of increased levels of blood glucose and/or blood pressure (e.g., Harris et al. 1999). Interestingly, the within-black group analysis showed that black men with diabetes were more likely to have had CHD diagnosis than black women with diabetes. This difference may reflect a need for specific educational interventions aimed at black women (Schoenberg et al. 1998). An unexpected finding was the greater likelihood of CHD diagnosis among black women with diabetes, compared with white women having diabetes. It is plausible that African American women tend to rely more heavily than whites on their informal social networks to meet their disease management needs and that social support is significantly associated with improved diabetes management among members of this population (Ford et al. 1998).

The impact of hypertension on CHD diagnosis among black men compared to white men with hypertension may in part be explained by the "John Henryism Hypothesis" (James et al. 1983; James 1994), which suggests that the well-known increased risk for hypertension in poor and working class African Americans could be due to their heightened exposure to social and economic adversity on the one hand and, on the other, to their strong behavioral predisposition to confront such adversity with determined, high-effort coping. A more physiological explanation may come from a recent study reporting that African Americans with high blood pressure have nearly double the risk for an enlarged heart (left ventricular hypertrophy) compared to their white counterparts with high blood pressure (Kizer et al. 2004). This increase in muscle mass in the heart's pumping chamber is due to an increased workload on the heart, and

is a strong predictor of heart disease, stroke, and death. Although cautious in offering an explanation for these racial differences, the investigators did speculate that because of unequal access to health care, the African Americans may have had the high blood pressure for longer periods than the whites (Kizer et al. 2004).

The significant relationship between frequency of depressive symptoms and CHD is well-established in the literature (e.g., Atho et al. 1997; Carney et al. 1999; Mills 2001). For example, research to determine the relationship between depressive symptoms and cardiovascular events found that the average level of psychological distress was significantly higher in coronary patients than in controls on all tests (Pignalberi et al. 1998). On an international perspective, Strodl (2003) found perceived stress to be a significant independent correlate of new diagnosis of symptomatic CHD in an older adult sample of Australian women. Additionally, the literature has consistently documented the greater frequency and higher levels of depressive symptoms among women, compared to men (e.g., Perlin 1989; Blazer et al. 1991; Mirowski 1996). However, the findings are ambiguous concerning differences in levels of depression among black and white women. Often, African American women are identified as being at high risk for depression. Yet, they also are perceived as either delaying or not seeking treatment for depression (Mills 2000). One explanation for the greater impact of black women's depression is a suggestion that African American women may see themselves as devalued within American society and may have fewer support systems to buffer stressful conditions (Warren 1994). Nonetheless, Mui & Burnette (1996) found that older African American women reported fewer depressive symptoms than their white counterparts. Yet their study suggests that physical illness, perceptions of unmet need, and a low sense of control were common predictors of depression. However, since heart problems involve treatment and medication and may result in limiting social interaction by possibly restricting mobility, a result is increased frequency of depressive symptoms. Cardiac patients often report higher levels of social isolation, avoidance, and self-blame and more painful life events than controls (see Pignalberi et al. 1998; Steffens et al. 1999). Potentially, the social expectations placed on women's roles, social isolation, and restricted mobility may account for the significant relationship between depression and CHD for women.

VII. CONCLUSION

Explanations for the variance in the prospect of a physician diagnosis of CHD are complex and include social, behavioral, environmental, genetic, and physiological reasons. Researchers have found evidence in support of a genetic predisposition contributing to some aspects of cardiovascular health, which helps to explain a significant amount of the racial/ethnic and gender variance in risk factors (American Psychological Association, 1997). Yet, it is the manner in which predispositions interact with the environment that determines the extent to which they may become manifest, recognized, and treated. Social, behavioral, and psychological factors such as the thoughts and actions of patients, support networks, and healthcare practitioners are important in activating the gene-environment interaction, and warrant careful consideration. The findings of this preliminary study also point toward a continuing need to develop and improve prevention programs tailored to the education, ethnicity, and other characteristics of populations at increased risk for CHD. As an example, among many women, misperceptions still exist that cardiovascular disease is not a real problem for women, particularly CHD and stroke, which continue to be the leading causes of death of women in the U.S. and most developed countries. Continued educational interventions for physicians and other healthcare providers also are necessary to assist these professionals to better integrate cultural competence and sensitivity into their practices, which will improve the quality of preventive care, and lower morbidity and mortality attributed to cardiovascular disease in general, but particularly CHD for black men and women.

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PERCEPTIONS AND BELIEFS ABOUT TYPE 2 DIABETES AMONG NON-DIABETIC BLACK WOMEN

Mary Shaw-Perry, Ph.D., CHES

I. ABSTRACT

Racial and ethnic disparities have existed in America since the birth of the nation. A vital part of working toward the elimination of racial and ethnic health disparities lies in understanding the *lived experiences* of those deemed high risk for preventable diseases such as type 2 diabetes. Few studies have explored the perceptions and beliefs that non-diabetic African American women have about type 2 diabetes and secondary complications that result from this chronic disease. The purpose of this formative research study was to involve African American women in focus group discussions to elicit their perceptions and beliefs about diabetes and to generate ideas for developing diabetes education, risk reduction, and screening programs tailored to African American women.

The study population consisted of low- and middle-income African American women with no personal history of diabetes that resided in two urban, northeast Texas counties. Twenty-eight African American women between the ages of 25 and 65 were recruited through the assistance of two churches, a beauty salon, and a public health clinic. Participants' perceptions reflected knowledge of the severity of complications resulting from untreated diabetes, but a lacked an understanding as to why these complications occur. Participants lacked knowledge about (a) signs/symptoms of diabetes, (b) how to access screening for the disease, and (c) reported being uncomfortable asking physicians questions about diabetes and requesting written information and tests for the disease.

These findings suggest that efforts to eliminate disparities in health and health care must begin with health promotion and policy reforms that will improve education outreach and engage communities in the design and implementation of health education programs, the organization and delivery of preventative care services, and the evaluation of all health services.

KEY WORDS: minority health, type 2 diabetes, African-American women

II. INTRODUCTION AND BACKGROUND

Concerns regarding racial and ethnic disparities in health have dominated recent discourse among health professionals; however, health disparities have been a long and disturbing reality for people of color in the United States. For example, the prevalence of diagnosed diabetes in African Americans has tripled during the past 30 years. According to the National Medical Expenditure Survey 1992 (Peyrot & Rubin, 1992), more than \$100 billion is spent annually in the U. S. to care for people with diabetes. In 1998, 1.5 million out of 35 million African Americans had been diagnosed with diabetes. This is almost four times the number of African Americans known to have diabetes in 1968 (National Institute of Diabetes and Digestive and Kidney Diseases [NIDDKD], 1999). Braithwaite & Taylor (2001) reported that diabetes is the third leading cause of death in African Americans. According to the American Diabetes Association, diabetes is the fifth deadliest disease in the United, affecting 2.7 million or 11.4% African Americans aged 20 years or older (American Diabetes Association [ADA], 2005b).

Persistent health disparities are well-documented among minorities and women of color. One in four African American women over the age of 55 has diabetes, nearly twice the rate of white women (National Women's Health Information Center [NWHIC], 2000; McNabb et. al., 1997). Non-insulin-dependent diabetes mellitus (NIDDM), or type 2 diabetes, and the severity of complications that develop secondary to the disease represent a major health problem that contributes to the health disparities existing between African American women and other groups (U.S. Department of Health & Human Services, 2000). There are several risk factors associated with the frequency of diabetes in African Americans and other populations (NIDDKD, 1999).

The first is genetics, which includes inherited traits and group ancestry. The second is medical risk factors, including impaired glucose tolerance, hyperinsulinemia, insulin resistance, and obesity. The third is lifestyle factors, including physical activity (NIDDKD, 1999, p. 1; Hu et al., 1999).

Delayed diagnosis is an additional risk factor associated with complications of diabetes, since the onset of diabetes can predate the clinical diagnosis for up to 10 to 12 years (McNabb et al., 1997). It is

unclear whether African American women perceive or believe that genetics, medical risk factors, and lifestyle factors may contribute to the development of type 2 diabetes. Much of the literature on black women and diabetes points to the importance of screening and early detection among high-risk women, and the need for improved quality of care and patient education services appropriate to the needs of these women. Clearly, low screening levels and late stage diagnosis contributes to poorer health outcomes when compared with the general population (Aman et al., 1998).

A review of the literature revealed that few studies have been done to determine the perceptions and beliefs that non-diabetic African American women have about diabetes and secondary complications that result from the disease. As a result of this gap in knowledge, there is a lack of culturally appropriate preventive programs or measures, including components for education, risk reduction, and screening that are tailored to African American women.

Therefore, the purpose of this study was to involve low- and middle-income African American women in focus groups to elicit their perceptions and beliefs about type 2 diabetes and to generate ideas for designing diabetes education, risk reduction, and screening programs tailored to African American women. Formative research utilizing focus group methodology as an assessment and program-planning tool for culturally specific diabetes education programs has been reported in the literature (Blanchard et al., 1999). Specifically, focus group methods are designed to discover the reality of a specific, well-defined population to meet their specific, self-defined needs (Blanchard et al., 1999, p. 819).

Although focus group studies reported in the literature have addressed perceptions, beliefs, and practices of African Americans living with diabetes, this methodological approach has not been used to explore the perceptions, beliefs, and behaviors of non-diabetic African Americans who may be at risk for developing diabetes. Morbidity and complications associated with late-stage diagnosis of diabetes will continue to be one of the health disparities unless screening and education prevention measures stimulate lifestyle behavior changes. The information gained from this study provides valuable information for the design, implementation, and evaluation of diabetes screening and education programs; diabetes education literature; and media messages to promote awareness, early detection, and treatment for diabetes.

III. RESEARCH QUESTIONS

The following research questions guided this study:

1. What are the perceptions and health beliefs about NIDDM (type 2 diabetes) among African American women?
2. What are the perceptions and health beliefs about the risk factors for developing NIDDM (type 2 diabetes) among African American women?
3. What are the perceptions and health beliefs about the severity/complications of NIDDM (type 2 diabetes) among African American women?

IV. METHODOLOGY

Focus group methodology was used to explore African American women's perceptions and beliefs about diabetes and to generate ideas for diabetes education, risk reduction, and screening programs tailored to African American women.

A. Population and Sample Selection

The study population consisted of low- and middle-income African American women who resided in urban, northeast Texas. For purposes of this study, the population was further delimited to African American women who (a) had no history of diabetes, (b) were self-defined as African American, and (c) were between the ages of 25 to 65. A convenience sample comprised of twenty-eight African American women was recruited through two churches, a beauty salon, and a public health clinic (WIC). Women meeting the eligibility criteria signed up at each site and were given an invitation to attend a scheduled focus group session. Four focus groups (6-10 women per group) were conducted during a four month period, one at each of the four sites from which the women were recruited.

B. Instrumentation

The Pen 3 model has been utilized by researchers to attempt to understand the complex array of perceptions, nurturers, and enablers that influence behavior and attitudes (Airhihenbuwa, 1995). Under the

guidance of a panel of diabetes prevention and care experts, the researchers developed an instrument composed of two parts: a demographic profile sheet and an interview guide. A demographic profile sheet based on National Health and Nutrition Examination Survey (NHANES III, 1988-1994)(Centers for Disease Control [CDC], 2001), and instruments developed by Shaw (1995) and Vaughan (1995) were used to collect selected information about the participants. Questions included the following items: (a) age, (b) last grade in school completed, (c) income, (d) religion, (e) exercise behaviors, (f) weight perceptions, (g) race/ethnicity, (h) family history of diabetes, and (i) marital status.

The focus group interview guide consisted of four open-ended questions, with two parts to be answered under each question to solicit information regarding participants' beliefs and perceptions about diabetes. The content validity of the interview guide was established through a panel of experts, composed of two African American diabetes health educators, practitioners from three northeast Texas diabetes patient care sites, and an additional out-of-state site, the Michigan Diabetes Research and Training Center (MDRTC), which works with the African American community to screen for diabetes, collect survey data, and promote diabetes awareness and education.

Table 1. Focus Group Interview Questions

1. What do you believe are the major health problems of African American women?
 - a. How does diabetes affect African American women?
 - b. What health practices can you do today to be healthy and prevent or reduce the chance of getting diabetes?
 2. What is diabetes?
 - a. How would you describe/define diabetes to someone else?
 - b. What do you believe causes diabetes?
 3. What are the three most critical factors (things) that contribute to the development of diabetes in African American women?
 - a. What do you believe happens if diabetes is not treated?
 - b. What problems develop from having diabetes over a period of time and not knowing it?
 4. What do you feel diabetes education programs should include?
 - a. How would African American women describe the seriousness of the disease? Why would they describe it this way?
 - b. What do you feel can be done to get African American women to participate in diabetes education and/or screening programs?
-

Procedures

Researchers obtained access to the population with the site managers' permission; the site managers also agreed to recruit clients who were accessing services during a three-week period. Potential participants were identified from weekly clients who expressed interest in the study based on informational flyers posted at each site. Clients expressing interest in the study were provided invitations and asked to sign up and provide a contact number. Site managers submitted the potential participant list to the researchers at the end of a three week recruiting period. The researchers contacted each potential participant, provided them with the scheduled dates for the focus groups and advised them that study participation was voluntary and that they had the right to withdraw from the study at any time without penalty or undue attention.

Three weeks prior to each scheduled focus group session, the site manager confirmed participant attendance, reserved room space, and arranged for the refreshments. All participants were advised that they would be provided a consent form to participate in the study and that consent to audiotape during the discussion was included in the general

consent form. Provisions were made to conduct an individual interview if a participant preferred not to be audiotaped.

Each participant was asked to complete the demographic profile sheet prior to the start of each 1½ hour session. The facilitator used the interview guide script to narrate each session, always providing an explanation to participants about the purpose of the permission form and a rationale for signing the permission form. Additionally, the experienced facilitator provided ample time for participants to ask questions about the purpose of the study. The facilitator also explained that answers provided to the research questions would serve as a guide in developing strategies to recruit women into diabetes education and prevention programs by identifying effective approaches.

During the sessions, the facilitator recorded responses to the questions either on a flip chart with a marker or onto a data collection form if a modified interview style technique was used. A scribe also recorded responses independent of the facilitator, and each session was audiotaped. A transcript of each taped session was prepared by the researcher. The researcher reported themes that emerged under the following categories:

1. Perceptions and beliefs about type 2 diabetes or NIDDM.
2. Perceptions and beliefs about risk factors for type 2 diabetes or NIDDM.
3. Perceptions and beliefs about the severity/complications of type 2 diabetes or NIDDM.

Food was provided during each session and participants received a beauty product as a thank you gift. Each was also eligible to win one of two door prizes, a watch or a camera, through a drawing held at the end of each focus group session. Additionally, participants received a certificate of completion and a thank you letter in the diabetes education packet provided at the end of the session. Time was then allowed for participants to ask the nutritionist and diabetes educator specific questions about prevention, screening, and/or treatment of diabetes. Within two weeks of each session, thank you letters were sent to the facilitator, the agencies that offered professional advice during the course of the study, and the contact people at each focus group site.

C. Data Analysis Methods

Data from the demographic profile instrument were compiled and entered using SPSS crosstabs, a Statistical Package for the Social Sciences (version 10.0). Descriptive statistics were used to characterize the sample. Audio recordings of each focus group were transcribed verbatim by the researcher with each review occurring in a timely manner following the session to maximize observations, discussion climate, and recall. Two experienced qualitative researchers assisted with reviewing and comparing transcriptions, facilitator-recorded flip chart responses, and the scribe's hand written field notes. A complete list of responses based on the audio transcriptions, flip chart, and scribe's notes provided the complete data set that was eventually used to identify the significant themes.

Data from participants in each focus group session were separately analyzed for individual group responses, but grouped together for a composite analysis. The facilitator, the researchers, and one other health professional completed the content analyses of the transcripts. Using large sheets of butcher paper, supporting focus group questions were grouped under each guiding research question. Participant responses were grouped under each focus group question. Each reader then identified themes of the data set specific to each focus group question, and indicated specific quotes that were particularly representative of the themes. Themes were defined as topics that were discussed more than twice within each focus group discussion.

Repeating themes or ideas were noted by marking the data with symbols. Common phrases were used to further develop analysis. Particular words or phrases used by participants to describe experiences and that were repeated at least twice were grouped and circled under the focus group question to identify repeat themes. These were then listed and grouped together by similarities. The frequency of statements (words or phrases) made per theme group was counted. Statements with a frequency of three or greater supporting a theme were placed into a text box, and the recurrent themes were numbered and listed under the text box.

Table 2.**Research Question 1: What are the perceptions and health beliefs about NIDDM (type 2 diabetes) among African American women?**

Question: Focus Group Question 1: What do you believe are the major health problems of African American women?

- (a) too fat
- (b) obesity/overweight
- (c) high blood pressure --from cooking with too much fat
- (d) other: Stress --single parents/divorced/children in family
- (e) AIDS/Lupus/sickle cell
- (f) cancer (especially ovarian and breast)
- (g) diabetes
- (h) heart Problems
- (i) Put self last/postponed Dr. visits --no self-care

Responses: Focus Group Question No. 1

The recurrent themes that emerged from focus group question 1, **the major health problems of African American women**, were (1) hypertension and heart disease, (2) obesity resulting from a high fat diet, and (3) cancer (especially breast).

Table 3.

Research Question 1: What are the perceptions and health beliefs about NIDDM (type 2 diabetes) among African American women?

Question: Focus Group Question 2b: What do you believe causes diabetes?

- (a) heredity/trait
- (b) obesity/overweight
- (c) race/chemical make-up (African Americans, Asians, Hispanics)
- (d) how food cooked/food prep/what you eat/cooking/diet-too many sweets, rice
- (e) food cooked – salt, bacon
- (f) poor diet/eating habits
- (g) not being aware: no self-education
- (h) believe it won't happen to us
- (i) not an issue “until it's at our back door”
- (j) not seeing a doctor routinely
- (k) how raised
- (l) family hx
- (m) too many sweets/red meat/pork
- (n) not enough vitamins
- (o) not enough exercise (couch potatoes)
- (p) potatoes, starch turn to sugar
- (q) not eating well balanced diet
- (r) lifestyle
- (s) poor circulation/bad circulation of the blood
- (t) not enough rest HBP

Responses: Focus Group Question 2b

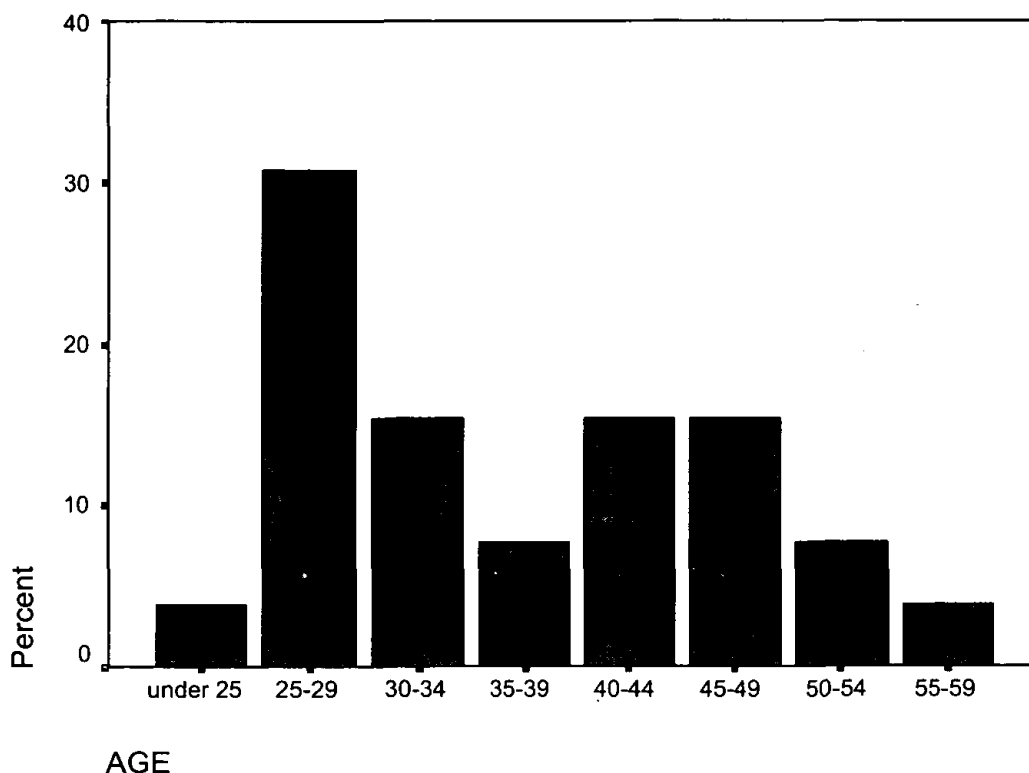
The recurrent themes that emerged from focus group question 2b, **the causes of diabetes, were** (1) heredity, (2) obesity/overweight, (3) poor diet, and (4) lack of exercise.

Results

A total of 28 African American females participated in the study. Two participants were disqualified from participation because of self-reporting a previous history of type 2 diabetes on the demographic profile sheet collected prior to the beginning of each session. The sample

population consisted of women 25 to 65 years of age, with the exception of a participant in the third focus group who was 21 years of age. As shown in Figure 1, the largest number of participants, approximately 31 percent, were drawn from the 25-29 age group.

Figure 1. Age group distribution of focus group participants



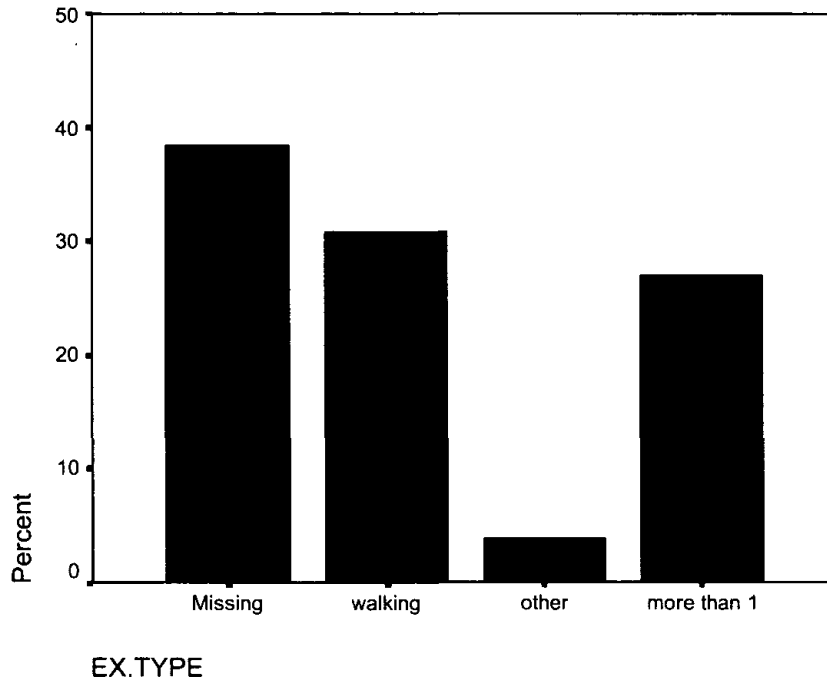
Note. Distribution consists of 26 total participants from four focus groups. **Approximately 42 percent of the participants were married and 38 percent of the participants graduated college, and approximately 8 percent attended graduate school. Religion was described as strongly influencing the daily lives of 77 percent of the participants.**

Lifestyle habits such as diet, exercise, and activity are modifiable risk factors. Modifiable risk factors were addressed by asking questions about exercise, activity, body weight perceptions, and diabetes perceptions on both the demographic profile sheet as well as in the focus group questions. Non-modifiable risk factors were addressed in the demographic profile and the focus group questions.

Sixteen participants reported they exercised, while ten participants claimed they did not exercise. Exercisers reported engaging in exercise an average of three days per week and an average of 48 minutes per exercise session (Figure 2). Eight participants, or 30.8 percent, claimed to participate in walking, and seven participants, or 26.9 percent, reported performing more than one type of exercise. Other than walking, no other types of exercises were identified by the participants. In the focus group setting, activities such as chasing children were considered a form of exercise by participants. Housework was cited as a physical activity by

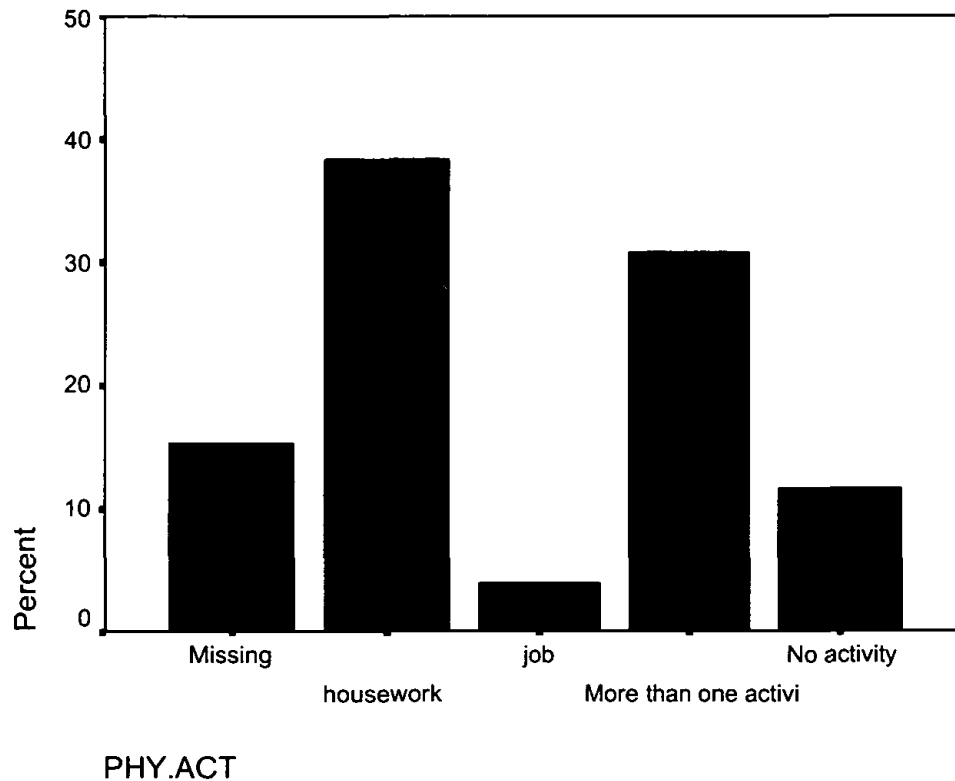
more than 80 percent, or 21 of the participants. Refer to Figure 2, which illustrates the types of exercises performed by participants, and Figure 3, which illustrates types of physical activities performed by participants.

Figure 2. Types of exercise reported by participants



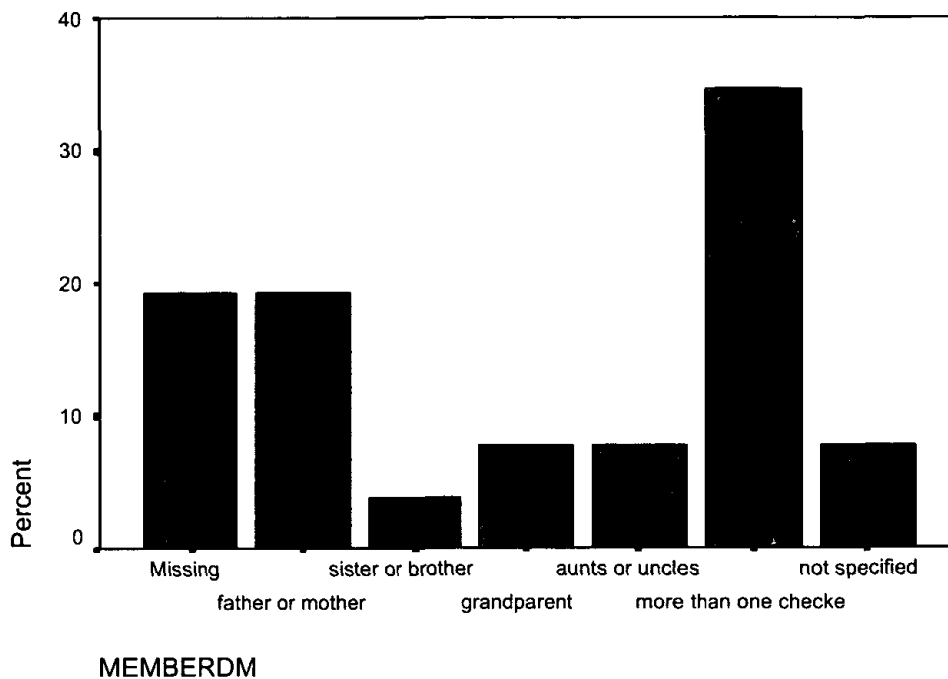
Note. Types of exercise included walking, other, and more than one activity. Ten responses were left blank as participants indicated that they did not exercise.

Figure 3. Types of physical activities reported by participants



Note. Types of physical activity included housework, gardening, and sewing. Four participants left this question blank.

Twenty-one (81 percent) of the respondents indicated they had a family history of diabetes with approximately 40 percent perceiving themselves at risk. Figure 4 reveals the distribution of family members reported as having diabetes.

Figure 4. Family members reported as having diabetes

The focus group findings revealed that participants having family members with diabetes have a higher awareness of the seriousness and severity of diabetes than participants who do not have family members with diabetes. Additionally, all of the participants expressed concerns about diabetes-related complications such as amputation, blindness, and death due to personal experiences.

Limitations

The study was limited in scope by the small sample size; therefore, generalizability was decreased. Additionally, the study was limited to the inclusion of only African American women who self-reported that they have never been diagnosed as having diabetes. The sample was drawn from one metropolitan area in the southwestern region of the country, which may not reflect the perceptions, beliefs and experiences of all non-diabetic African-American women.

V. DISCUSSION

Diabetes and the severity of complications represent a major health problem, which contributes to health disparities that continue to exist between African American women and other groups (U.S. Department of Health & Human Service, 2000). This study examined the perceptions and

health beliefs among African American women in regards to NIDDM (type 2 diabetes), risks factors for developing NIDDM (type 2 diabetes), and the severity/complications of NIDDM (type 2 diabetes) in an effort to generate ideas for diabetes education, risk reduction, and screening programs tailored to African American women.

Study participants believed that stress may lead to diseases, such as high blood pressure, diabetes, and cancer. They also reported that inadequate rest, poor diet, and not exercising were factors that lead to the same diseases. Although walking (Figure 2) was indicated as an important form of exercise for African American women, normal routine activities such as housework (Figure 3) were also considered to be a significant form of exercise. Obesity and heart problems were perceived as health issues for African American women. Death and amputations were popular beliefs of common occurrences from diabetes, especially given personal family experiences with diabetes-related deaths and complications. While 80.8 percent of participants identified a family history of diabetes, only 38.5 percent perceived themselves to be at risk for developing diabetes. Participants mentioned that genetics, race, and physical make-up played a role in developing diabetes. Severity and complications of diabetes, such as vision loss and amputations, emerged as repeating themes regardless of whether the focus group questions were addressing general diabetes beliefs, or diabetes beliefs related to severity and complications.

Data analysis revealed that participants viewed diet as a factor in preventing diabetes; specific themes identified included the need for consuming fewer carbohydrates, drinking more water, limiting salt, limiting certain meats (such as pork), and losing weight. The study listed exercise; weight loss; and limiting starch, pork, fat, fried foods, sugar, and carbohydrates as health practices that may prevent or reduce the risk of getting diabetes. Obesity was listed as a major health problem of African American women and a contributor to diabetes. Food item selections rather than overeating were stated to contribute to obesity. Study findings confirmed what the literature reports, namely that many African American women consider weight loss to be appropriate for health improvement, but not necessarily for appearance (Haire-Joshu, 1996; D'eraimo-Melkus, et al., 1996). Beauty shop participants indicated that an overweight person was considered to be 50 pounds above normal weight, and an obese person 100 pounds above normal weight. Two-thirds of the participants in the study indicated dissatisfaction with their weight

Participants recommended that reading simple diabetes-related literature and attending health fairs would help women of color become more knowledgeable about diabetes and how to reduce risk. They also

reported awareness that healthy eating habits and increased physical activity may prevent the onset of diabetes. Food choices selected were identified as contributors to the body's control of sugar increase or decrease. Blood pressure or blood circulation in combination with an increase or decrease in blood sugar levels were noted as causes of diabetes.

Suggested sites for health screenings and exercise classes included churches, health fairs, community centers, grocery stores, and WIC clinics, schools, and other public health clinics. None of the participants were aware that free diabetes screening programs were offered in a local neighborhood convenient to two of the focus group sites. Transportation and childcare issues also surfaced as concerns for getting to or being able to attend community programs.

Finally, many of the focus group participants concluded that health care was too expensive, there were too many preventative health service sites to visit (not all services under one roof), physicians did not talk at their level, and that simple written materials were not provided. Participants generally expressed knowledge of the severity of diabetes and its secondary complications, including heart disease, renal failure, kidney disease, blindness, and amputations.

VI. CONCLUSIONS AND IMPLICATIONS

Although this exploratory study provides information that may be useful in designing, implementing, and evaluating diabetes education and screening programs for African American women, the reality is that the problem of health disparities extends beyond perceptions and beliefs of health consumers. The information derived from this study will need to be considered by transdisciplinary teams of researchers, practitioners, policy makers, and even the community before the elimination of the unequal burden of type 2 diabetes among African Americans becomes a reality.

Among African American women, the primary resource for learning about diabetes and its implications is from other African Americans — family members, friends, co-workers, and church family. African American women who are living with diabetes should be trained and utilized to deliver accurate information as *lessons to be learned* based on their experiences. The importance of family story sharing should not be minimized as an effective strategy in the campaigns to promote awareness and information exchange (i.e., move women into the contemplation stage of changing modifiable behaviors that ultimately contribute to the onset of NIDDM or type 2 diabetes). Structured social support nurturers (informed

and functional) can potentially influence perceptions and beliefs about diabetes among non-diabetic women.

Health beliefs and behaviors are the result of how people receive, process, and decide to act on information, resulting from the complex interaction of perceptions, enablers, and nurturers that signal the need for behavior changes within a family and communal structure. Community health educators, health care providers, voluntary health organizations, and other stakeholders should consider the following suggestions when designing culturally appropriate interventions aimed at preventing type 2 diabetes among African American women:

- 1) Partner with existing community organizations such as the African American church, beauty shops, nail salons, schools, and sororities to encourage diabetes screening and the adoption of healthy lifestyle behaviors
- 2) Utilize the family system to encourage younger African American women to participate in early detection screening programs.
- 3) Provide forums for participatory dialogue to answer questions and offer support for modifying lifestyle behaviors to reduce risk for the onset of type 2 diabetes.
- 4) Use peers to support behavior change -- eating healthier and exercising regularly.
- 5) Develop lay health community advisors to provide accurate and reliable type 2 diabetes prevention information.
- 6) Compile a resource inventory of affordable community services that support lifestyle behavior change, provide screening, and offer treatment if needed.

This formative research study reveals the importance of analyzing *lived experience* stories which convey information about perceptions, beliefs, and behaviors of African American women considered high risk for developing type 2 diabetes. The author finds that people clearly make decisions about seeking preventive care services either on their own, or

with support from others. Some people muddle their way into the preventative care system or let others (family members, friends, significant others) push them to seek preventative care. Type 2 diabetes is a preventable disease — clearly linked to lifestyle behaviors. Lifestyle behaviors among African American women are linked to social networks that include family and community. Informed, structured social networks that are large and closely tied together have the social capacity to get individuals into preventative care services and enhance opportunities for African American women to adopt healthier lifestyles. Whether African American women will engage in healthy lifestyle practices (healthy eating habits, exercise, and weight management) to reduce or delay the onset of diabetes may depend on their perceptions and beliefs about diabetes, its severity, and informed, structured social support networks developed through culturally appropriate interventions that consider the cultural norms, beliefs, and values of the community. These informed, structured social support networks may encourage African-American women to engage in self-regulatory behaviors that decrease risk for the onset of type 2 diabetes.

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MENTAL HEALTH STRATEGIES TO ELIMINATE HEALTH DISPARITIES: TOWARDS THE CREATION OF A CLIMATE AND CULTURE OF OPTIMAL HEALTH FROM AN AFRICAN (INDIGENOUS) AMERICAN PERSPECTIVE

Linda James Myers, Ph.D.

I. ABSTRACT

Many scholars and practitioners concerned about the health of all people question how best to move beyond a history of bias and mono-cultural strategies when it comes to overcoming disparities in health care between African Americans and European Americans (USDHHS, 2001). This presentation introduces the results of a multilevel, community participatory research/demonstration project which explored what optimal health is and developed strategies for how best to achieve it, both personally and collectively, in a toxic, oppressive environment of continued social and economic injustice and disenfranchisement (Myers, 2003). The psychology and model of optimal health which emerge offers a process for transforming human consciousness and the institutional structures it creates, to reshape our health outcomes. With this strategy, regard for, access to, and improvement of quality health care may not only be more balanced, but also dramatically improved for all groups.

While the United States of America has accomplished much over the past two hundred plus years, the area of health and health care has not been an area of great strength. Although it is one of the wealthiest nations in the world, the United States ranks only 72 in terms of the quality of health care it provides its citizens. Given the history of the United States, it should come as no surprise that even with this generally low performance, a major disparity in health care still exists between African Americans whose ancestors' forced labor built this country and European Americans who benefited from their labor. For these people of African descent, whose ancestors for generations experienced the legally and socially sanctioned terrorism of chattel enslavement, careful examination of the society's construction of health is warranted with particular attention to the implications of these constructions for the health of the group. This article will explore the results of a multi-level, community participatory research/demonstration project which examined what optimal health is and how best to achieve it, both personally and collectively, in a toxic, oppressive environment of continued social and economic injustice and disenfranchisement.

To some, this assessment of our history and the current social environment may seem harsh and the immediate reaction may be defensive. However, what we have learned through this project is that only through confronting the worst of what ails us can we move on to health. As an old Ethiopian proverb states, "He who conceals his disease can not be healed."

Giving voice to this reality that has been denied for far too long is not intended to lay blame nor make excuses, but rather to provide an explanation heretofore disregarded and foster the understanding needed to move us all forward in better health. Successful forward movement into the future is impossible without confronting the most powerful forces shaping the future, the present and the past. Taking responsibility for that over which we have control then becomes the next step in achieving optimal health.

II. NECESSITY AND VALUE OF A CULTURALLY GROUNDED ASSESSMENT

Seldom heard is the perspective of Africans in America whose cultural identification at the level of values, beliefs, and assumptions, or cultural deep structure, is more in line with the traditions of Native, First Americans, the indigenous people, rather than European Americans, the colonizers. From an African (Indigenous) American perspective, health is a cultural issue, requiring collective action, not just individual behavior change. There is an awareness that the collective will influence the environment in which good health is likely supported or disrupted. From social policies and practices that allow pollution of the air and water, the production and sale of carcinogenic food, the burial of toxins, the fostering of addictions, and so forth, to the prevalence of domestic and non-domestic violence, the values, perceptions, thoughts, and actions of people have great bearing on health.

Intended as a training guide for those who are ready for the next level of development, my having done the critical self-reflection and analysis necessary for an honest assessment of the status quo, this manual may be used in multiple ways. Persons in educational institutions, governmental and professional organizations, businesses, and other formal groups can engage in trainings using the format outlined and the collective processes identified to achieve the goal of improved health in all areas of personal and communal life. Leaders and lay individuals can create informal groups that use the guide for their own support and self-help processes. Whether organizations use it for facilitated training or as a

discussion springboard, or individuals use it for independent study and self-development or as a guide for group process, the goal is to stimulate thinking, motivate to action, and organize to stand for improved health and social justice.

III. SOCIO-CULTURAL CONTEXT

Dr. John Chissell (1998) defines optimal health as the best possible emotional, intellectual, physical, spiritual, and socio-economic aliveness that we can attain. Ideally, our way of life or culture would be holistically devoted to creating the kinds of environments, both social and physical, that would maximize the likelihood of good health. In order to be most functional, a health care system would ideally be comprehensively, cohesively, and coherently organized to influence the best possible aliveness we can attain. Such a system would require a unified model of health that includes the integration of the natural or physical environments, social environments, ancestral inheritance both physical/material and psycho-cultural/psycho-social, and planning for future generations. It would need to be driven by a comprehensive, cohesive, and coherent way of viewing the world and understanding of how life and health work, or at least a good working theory. Our African and Native American cultural heritages, as well as the height of this society's scientific research, all point toward a similar unified model of health. Yet the model driving our social and health policies, decisions, and practices is not as unified.

IV. PURPOSE AND PERSPECTIVE OF THE TRAINING GUIDE

The production of a training guide and model for creating a climate and culture of optimal health from an African (Indigenous) American cultural perspective is one outcome of Project Sankofa. The purpose of this guide is to provide culturally grounded information and understandings for improving health and health behaviors in the African American and all communities. It brings research and scholarship to bear on ways in which African Americans and others can empower themselves to live the healthiest, happiest, and most successful lives possible in the face of a social context that has otherwise been toxic and often hostile.

While targeting the enhancement of health using an African (Indigenous) American cultural frame of reference, the model has relevance for other populations with similar social issues in context and

similar value orientations in conflict. The model may be very useful in improving health efficacy and working with members of oppressed and dominant groups internationally. The keys to applicability will be an open mind and the willingness to push through the psycho-social barriers to engaging in difficult dialogues for the purposes of healing and growth. Further, the African American community is neither monolithic nor homogenous. Therefore, there may be those, particularly the more highly assimilated and acculturated among us, for whom this guide does not speak or resonate. Readiness in terms of developmental processes is often contingent on degree of self-knowledge, past experiences, and exposures.

I am deliberately presenting the perspective of those whom I have touched in our multi-level, community participatory research/demonstration project, Project Sankofa. This group has an African cultural identification and an American cultural identification more in line with Native or First American cultural traditions, values, and beliefs than European American. They value family and community and are most concerned about the children and their health and education. They are very aware that most programs targeting and operating in the African American community are shaped by theories and methodologies that are not grounded in a culturally consistent health paradigm and are quite limited in their effectiveness, significance, and value.

The use of culturally consistent approaches by mainstream providers in working with ethnic minority populations in this country is in its early developmental stages. Historically the dominant culture's frame of reference has been assumed universal and has been applied as if so. Cultural infusion reflects the extent to which ethnic/cultural characteristics, experiences, norms, values, behavioral patterns and beliefs of a target population, as well as relevant historical, environmental, and social forces, are incorporated in the design, delivery, and evaluation of targeted health promotion materials and programs. The two cultural dimensions of greatest concern are the surface structure (i.e., visible aspects such as language, dress, diet, clothing, music, etc.) and deep structure (i.e., values, beliefs, philosophical assumptions, etc.).

Research looking at program effectiveness suggests that whereas surface structure generally increases the receptivity, comprehension, or acceptance of messages, deep structure conveys salience. Surface structure establishes feasibility, whereas deep structure determines program impact. Almost thirty years ago, I began to build my research around the strengths of African cultural tradition and its relevance for contemporary African American lives. What I found was that from the level of cultural deep structure, a theoretical framework emerged that

spoke to health, resilience, and positive psychology in ways that are just now being acknowledged, investigated, and confirmed by mainstream American psychology and social science. From Oneness, a Black model of psychological functioning developed in the seventies, to a theory of Optimal Psychology based on its premises in the eighties, I, along with other black psychologists, committed to cultural congruence in terms of study, analyses, theory, and interventions. This commitment has yielded research and interventions that can offer an improved climate and culture of health, individually and collectively; however, increased training opportunities are needed. An added bonus of these endeavors is the inherent universality of going back to the collective African beginnings of humanity and civilization to bring forward values and beliefs salient across cultural groups, but non-dominant in most in this modern/post-modern era.

Good health is inextricably tied to questions of human development in all spheres of life, including at a minimum, the psychological (i.e., the emotional, intellectual, moral, and spiritual), physical, and socio-economic. The psychological sphere, which involves our perceptions, values, thoughts, feelings, and subsequent behaviors, has been demonstrated to be the most powerful in determining health outcomes, as well as informing all other areas. This sphere directly shapes and is shaped by the society/culture in which we live, the worldview and values to which we adhere. With this interplay, we can see that where we are health-wise is reflective of our individual and collective development in the psychological sphere.

Take for example what some consider to be the most critical public health issue facing this country—terrorism. It provides the perfect illustration of the interdependent nature of personal and collective health and the importance of mental health and psychological development for health outcomes. While the interrelationships may be less obvious in terms of cancer, diabetes, cardio-vascular disease, or HIV/AIDS, upon closer examination it becomes evident that all share common factors. Those factors include: 1) a social/cultural context that supports conditions contributing to the disorder; 2) a psychological orientation that promotes either a holistic and integrative or fragmented and piecemeal approach to addressing disorder; and 3), the necessity to stretch toward an understanding greater than personal ego concerns to find meaningful resolution to the disorder. This African (Indigenous) American perspective seeks to contribute to improving our health and psychological development by offering culturally infused direction and instruction on creating a climate and culture of health.

African cultural values practiced in the American social context have been demonstrated to be a source of strength and resilience. They are undergirded by principles just now being discovered to be psychologically sound and healthy in Western psychology and behavioral health research (e.g., faith and hope). They can account for our still standing in the face of a long history of relentless terrorism, perpetual assaults on our culture and our character, and the multiple generations of psychological trauma, which continues to be inflicted daily. Recognizing resilience is a defining force relevant to all health outcomes and that adversity can either build strength or destroy; this guide will advocate for the use of struggle and adversity as a springboard for reaching the next level of human development, improving health and quality of life.

V. HEALTH IN BLACK AND WHITE

The collective experiences of racial/cultural groups in this country have been different; that of Black and White Americans, almost totally opposite. The difference in experience has been, for the most part, shaped by the relationship between values for personal material gain at the expense of others and understandings of human development (i.e., what it means to be human). For some cultural groups the pattern of higher value for material gain rather than compassion and responsibility for the health and well-being of others is a tradition. To illustrate the point, a knowingly crude historical overview along racial lines might be informative.

The history of the majority of blacks in America can be described as that of a people who for over four hundred years, generation after generation, have been exposed to extreme violence and terrorism from the group in political power. Denied even the most basic human rights for most of their history in this country by the way of legally sanctioned and socially endorsed bias, African Americans continue to be devalued and dehumanized by institutional policies and practices rooted in a non-comprehensive, non-cohesive, and incoherent mono-cultural world view. Focused almost exclusively on a material universe versus a spiritual/material one, inattentive to the interrelated and interdependent nature of all in the cosmos, and without consistency and whole-sighted (i.e., engaging heart, mind, and soul) reason, this world view full of contradictions allowed the claim of freedom and justice for all, when in reality it meant whites only.

The history of whites in America as a collective is that of a people who have for over four hundred years, generation after generation, been exposed to the economic advantages that come from having taken over

another people's land (colonization) and having enslaved and forced the labor of another group to build personal economic wealth. Social policies and practices have been institutionalized to favor and meet the perceived needs of this group. They benefit from the privileges of a social system that enthusiastically acknowledges, endorses, and reinforces their racial/cultural perspective.

The position of African Americans in this society is unique, with the potential of becoming universal. For example, everyone in the society may now experience a small sense of some African Americans' historic status of living under overt terrorism. African Americans' current disfavored status carries with it a long history of living under a system of legally sanctioned terror where they enjoyed virtually no human rights or civil rights, the latter of which were achieved less than forty years ago. Who would not doubt the capacity of the prevailing European American health care system to meet the physical and/or mental health needs of African American populations?

In order to demonstrate effectiveness, considerable enhancement of the sick care system is required. Interventions to prevent negative health choices and maximize positive health outcomes, restoring resilience to African American families and communities—particularly the most educationally and economically disenfranchised—are most effective when they are culturally sensitive and comprehensive. More culturally infused programming is needed, such as that proposed by the current model, which takes a holistic, integrative, and culturally congruent approach.

Despite African American families having achieved the right to equality under the law over thirty-five years ago, the effect of the prevailing racially biased, often covertly and overtly hostile, social environment on our health remains toxic. Even controlling for socio-economic class differences, progress toward first-class citizenship has yet to yield a close in the gap between the races in terms of regard for quality of and access to health care. The U.S. Surgeon General's report on ethnic and minority health, particularly his supplement on mental health and ethnic minorities released in Fall 2001, makes clear the need to develop and offer services designed specifically to meet the needs, cultural realities, and experiences of each population. Achievement of this goal will require the development and implementation of methods for creating a climate and culture that supports good health in African Americans' communities and addresses the impact of psychological trauma.

VI. CULTURAL INFUSION IN APPROACHES TO HEALTH

In the early nineties, the Association of Black Psychologists published an African-Centered Behavior Change Model to fill a void in terms of the HIV/AIDS/STD prevention training process. Funded by the Centers for Disease Control, the model developed was based on constructs and theories that had been explicated by black psychologists since the early seventies. Grounded in the self-conscious centering of psychological analysis and applications in African reality, culture and epistemology, our African-Centered Psychology encourages the examination of processes that allow for the illumination and liberation of the human spirit, psyche, or soul. Myers' theory of Optimal Psychology and the Unified Health Model (UHM) presented in this guide are both inextricably tied to this history of psychology. Echoing the Africana womynist voice of Maat (i.e., Black Goddess associated with the embodiment of truth, justice, and righteousness; divine order) in present day, both the theory and the model serve to restore feminine balance and bring a more comprehensive understanding of the reality of the primordial Black Mother.

Relying on the principles of harmony within the universe as a natural order of existence, African Centered Psychology recognizes: the spirit that permeates everything that is; the notion that everything in the universe is interconnected; the value that the collective is the most salient element of existence; and the idea that communal self-knowledge is the key to mental health. African-Centered Psychology is ultimately concerned with understanding the systems of meaning of human beingness, the features of human functioning, and the restoration of normal/natural order to human development. As such, it is used to resolve personal and social problems to promote optimal functioning.

As of late, there is increased awareness that such congruence is essential to successful programming. From program activities and service delivery efforts to treatment modalities, cultural awareness must progress from sensitivity to competence and ultimately to cultural infusion wherein the whole process from conceptualization to funding support, implementation, and evaluation is specific to the needs of the targeted population. Such development is essential in the areas of health and education, although approaches speaking to the cultural realities and experiences of the dominant population are most often in place.

The Unified Health Model (UHM) is supported by the Association of Black Psychologists ("ABPsi") Model, which maintains that culture is a critical construct in the understanding of human functioning, and one's

behavior is largely determined by one's culture. Different cultures have different cultural teachings and ideas about what it means to be human.

The ABPsi Model identifies eight African American cultural precepts:

- consubstantiation—all things in the universe have the same essence
- interdependence—everything in the universe is connected
- unicity/egalitarianism—harmony and balance is the correct relationship between people
- collectivism—individual effort is a reflection and/or instrument of communal or collective survival/advancement
- transformation—everything has the potential to continually function at a higher level
- cooperation—the optimal way of functioning with mutual respect and encouragement
- humanness—healthy behavior is governed by the sense of vitalism and goodness
- synergism—the performance outcomes of cooperative effort will be greater than the sum total of individual effort

The UHM adds to these precepts the support of a theory and model of psychological functioning which bring the sacrifices and lessons mastered by African people surviving the Maafa (African Holocaust) in America and indigenous, Native people, to the fore in confirmation of their truth. The cultural themes of spirituality, resilience, egalitarianism, communalism, orality and verbal expressiveness, personal style and uniqueness, realness, emotional vitality, and musicality/rhythm, which permeate African American praxis, (re)emerge as central to individual and collective health. Their embrace through UHM provide the bases for moving beyond the pathology of negating, disrespecting, and/or diminishing the worth and dignity of others and ourselves by virtue of any human diversity marker. The roots of racism, sexism, classism, elitism, rankism, and so forth, are all the same, the insecurity fostered an externalized sense of identity and worth which kindles a need to be better than another in effort to establish one's own illusory value.

The UHM is grounded in a cultural tradition in which human authenticity and worth comes from being indisputably connected to that which brought us into existence (the divine creator) and the ancestors without whom we would not be. Those whose cultural tradition assumes

no such connection will evaluate people differently in terms of moral substance and behavior than people who do. When such a connection is assumed, the most healthy functioning human beings would be those in whom collective human will, via spirit, transcends (i.e., moves from one phenomenal reality to a higher level reality) and transforms (i.e., changes one condition to another condition) human consciousness to experience unity with the divine. When this understanding is the cultural substance of a people, yet the particular geopolitical and socio-cultural milieu has through terrorism served to deny, destroy, and negate that reality, psychological trauma is the result. The UHM outlines a process for the healing needed to restore health, mend the cultural breach inflicted through multiple generations of oppression, and inform steps to achieving the higher stages of human development.

VII. THE NATURAL ORDER OF MENTAL AND PHYSICAL HEALTH AND HEALTH BEHAVIOR

For those to whom it may have been unclear before, it is now evident that good mental health is a key to good physical health. Even Western science now shows that the immune system is compromised by psychological stress, recuperation is improved with positive attitudes, and placebos are just as effective as anti-depressant medications and surgeries to improve arthritis in some cases. An individual's own experience can let him/her know that in order to change any and all health behaviors from diet to safer sex to compliance with doctor's orders, it is one's mind and will that must take charge and direct one's emotions and behavior to conform to that which is in one's best health interest. An improved climate and culture of health is needed to support and reinforce good choices. The ancient sacred text was correct, "as a man thinketh, so is he." Relying on the teachings of our trusted and loved ancestors put us ahead of the game, if we go back and fetch the best of our inheritance. Western science is just now coming to confirm what has been known for thousands of years in other cultural traditions.

The descendants of kidnapped and enslaved Africans are faced with the most serious of paradoxes or illogicality when it comes to health in this society. For a group to achieve health (either mental or physical) in a society that has historically placed them in either a less-than-human, or at best, an unfavored status, is a major accomplishment. For example, in the not too distant past (as few as two to five generations) European American mental health professionals of the time unashamedly determined that if kidnapped, enslaved Africans tried to run away and escape their

captors, they were suffering from a mental illness, drapetomania. The dominant culture has historically perceived, diagnosed, and treated the sane behavior of African Americans as insane. Thus, African Americans whose ancestors were enslaved, face the dilemma of having to rely on a society to provide mental and physical health services without having demonstrated the capability to do so.

African Americans are faced with some very serious questions: Has the mindset that would allow such distorted, self-deceptive thinking about African American mental health by helping professionals trained in this society changed, and if so, how? What can and must be done to ensure our good health and that of future generations given the nature of the social context in which we find ourselves? How do we, now thirty some years after having gained equal civil rights under the law (1964 Civil Rights Act), develop trust and rely on a system of health care in a society that has never demonstrated an understanding of health and well-being based on anything other than its own reality, experience, and cultural perspective? What do we bring from our own cultural heritage that the dominant culture in this society is just now discovering? And how do we leapfrog over what they have failed to realize is faulty in their cultural orientation toward health to recapture and embrace the truths that have been our inheritance, ensuring our survival, that of our ancestors and future generations? These are the questions we will be addressing in this African (Indigenous) American guide to healing, recovery, and health.

VIII. LIVING WITH THE CONSEQUENCES OF PSYCHOLOGICAL TRAUMA

Most should agree that multiple generations of enslavement, lack of human and civil rights, the perpetual negation of one's race, ancestry and ethnicity, and the imposition of values and beliefs undermining one's sense of well-being through terrorist acts would be traumatizing. Shaking the foundation of one's sense of safety and trust, psychological trauma is an emotional shock that can create substantial and lasting damage. The greater the threat and the less prepared we are to handle the terrorism, the greater the impact. Psychological research looking at trauma confirms certain outcomes. Trauma creates a climate of isolation, abandonment, and separation. Traumatized people have difficulty with relationships, as trust is thwarted. Feelings of threat and uncertainty, and the disruption of general adaptive functions can lead to the production of negative affect, depression, and anxiety beyond which the individual can adapt. The essence of trauma has been described as the loss of faith that there is order

and continuity in life.

Over the generations, numerous scholars and researchers such as Edward Blyden, Carter G. Woodson, E. Franklin Frazier, Frantz Fanon, Naim Akbar, Wade Nobles, Thomas Parham, and others, have discussed the multi-faceted impacts of enslavement, colonialism, cultural imperialism, and racist terrorism on persons of African descent. Bruno Bettelheim, a Jewish psychiatrist observing fellow Jews performing the role of guard in Nazi concentration camps, coined the term “identification with the aggressor” to describe what happens to people who find themselves in oppressive circumstances for extended periods of time in which they foresee no escape.

Although African Americans whose identification has been in line with the cultural values and beliefs of their African ancestors have been resilient, they have also been traumatized by the multiple generations of physical and sexual abuse, brutality, and inhumanity inflicted on them. Any human being moved from a tradition in which unity with the creator and nature is the centerpiece, and the development of the cultural group is measured by how well it takes care of the most vulnerable within the group, would experience trauma in a social context without any humane standards of conduct.

The psychology of oppression process instituted through terrorism to take control of the African mind in order to make Africans profitable slaves, required moving them from their cultural center, and included at least five phases. First, through the most brutal and horrific forms of terrorism, the Africans were captured and convinced that their physical well-being (i.e., whether they lived, died, were raped, castrated, beaten, had food, shelter, clothing) was in the hands of their captors.

Second, in the strange land and alien culture of captivity, Africans were denied access to their cultural traditions, or at least its surface structure aspects which their captors could control. The use of their native languages, maintenance of their indigenous diet, spiritual practices and rituals, and family systems were disrupted, normal contact with socio-cultural supports were complicated or dislocated. Third, their culture and history were negated. Everything African was painted as savage, primitive, uncivilized, without merit. Fourth, the culture and history of the captors were elevated, such that the only cultural beliefs, values, and traditions acknowledged were those of the European. To be cultured and civilized in this society was equated with mimicking the European/European American. Fifth, a divide and conquer strategy was put in place, whereby the enslaved Africans were pitted against one another. Those who would do the slave captors bidding were rewarded

with lighter work loads (often overseer), better food, shelter and so on.

The trauma imposed through the psychology of oppression is still fully functioning today. The physical bonds of enslavement are gone (except the prison industrial complex and ill-conceived public housing projects), but the structures and processes for mental bondage are fully in place. Physical and economic well-being (now termed “success”) is still largely in the hands of the beneficiaries of the captors; denial of and/or limited access to true African history and culture still exists. Negative portrayals of Africans and the negation of African history and culture are still commonplace. The elevation of a European/ European American worldview and cultural tradition continues to make this country almost exclusively mono-cultural in its focus. The value and credibility of other cultural orientations is most often ignored or discounted. The centerpiece of racist oppression, creating intra-group disharmony through dividing and conquering by skin color privileging, educational and socio-economic access, and geographic heritage, has been so effective that it has caused some to conclude that the biggest problem we as African Americans face today is ourselves. The long-term consequences of these oppression processes are mentacide, the systematic destruction of a people’s mind and culture. Mentacidal people become self-destructive, these behaviors are manifestations of internalized oppression, “identification with the aggressor” or what is called in popular culture the “Willie Lynch” syndrome. Reversal of the psychology of oppression process is necessary for good health and healing.

The good news is that in response to this adversity, African Americans can be named the poster children for resilience. As a group, they have turned enough lemons into lemonade to bring a life and vibrancy to popular culture—indeed, one that the world seeks to imitate. They have maintained moral leadership in terms of the fight for equality and civil rights from which all in the society have benefited. Evolving over time, culture is complex and dynamic, within African American cultural tradition increased knowledge, wisdom, and understanding have been the result of adversity. Yet, as generations of African Americans become increasingly assimilated and acculturated into the values and beliefs of an oppressive dominant culture, considerable loss might also be expected. As African (Indigenous) Americans we have had the opportunity to witness the importance of the deep structures of culture—the values, beliefs, and assumptions, in resilience and the transmission of culture. With limited access to indigenous languages, diets, rites and rituals, and systems of organization, the surface structure of culture, African people went deep within their own consciousness and came forth

with an understanding only the deep structures of their cultural heritage could provide. This authentic cultural substance identified by ancient Africans (those ancestors known as Ethiopians, Kemites, or Blacks) as the basis of health, has been proven to hold integrity and validity today and can account for our incessant ability to rise in the face of untold oppositions.

Consistent with African-centered premises, Myers' theory of Optimal Psychology and UHM are rooted in the values, beliefs, and assumptions of the wisdom tradition of African deep thought, which can be traced from the beginnings of human culture and civilization to date (see, *Food for Thought*). This worldview supports the development of a unified model of health, which is comprehensive and much needed, as we seek to restore a more complete understanding of health matters. Like it or not, the health of each individual is tied to another. The enslavement of Africans was contingent on the health of Europeans who developed the market and other Africans who collaborated in the capture process. To the extent that one is unhealthy, the health of all is affected. As all health issues are at some level interrelated and interdependent, when exposed to the toxins of another, if not properly inoculated, survival and well-being is at risk. When possible, having those infected quarantined, is a useful strategy, depending on the nature of the disease. When both social and physical environments are infected with toxins, health issues become even more difficult and complex. The Unified Health Model (UHM) provides the opportunity for movement in the direction of a truly holistic, integrated approach to good health.

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LESSONS FROM AFRICAN AMERICAN HISTORY¹

Lois E. Horton

Effective educational strategies for promoting better health among people of color can draw on the lessons of African American history and culture. Black communities faced centuries of displacement, oppression, and discrimination. These hardships often took a physical as well as an emotional toll, and African Americans developed ways of coping with them. In order to survive, African Americans also developed institutions and practices that became cultural strengths. Understanding the historical role of such institutions as black churches and mutual aid societies and such practices as informal adoption and the reconstitution of extended families may suggest educational strategies that draw on the strengths of these communities.

Uless Carter was the son of a sharecropper in America's Mississippi delta in the 1920s. At the end of each year, the landowner charged the family for seeds and other supplies and deducted it from their share of the proceeds from the crop. Like a great many sharecropping families, they often found themselves having earned nothing or going deeper into debt, according to the landowner's accounting. One year, Carter's mother had kept meticulous records, and when the landowner informed his father that the family had earned nothing that year, he boldly disagreed. Faced with the evidence of the family's earnings, the landowner admitted the truth, but declared that he could not pay what he owed them that year because he needed the money to send his son to college. This so angered Carter's father that he packed up his family and left the plantation.²

The story of Uless Carter's family illustrates one continuing theme in African American history – the injustice of arbitrary authority, anger at that injustice, and the suppressed rage that was often necessary to black survival. It also illustrates one of the ways in which the life circumstances of African American people have had an impact on black emotional and physical health – the necessarily suppressed rage at such injustice undoubtedly contribute to hypertension and depression.

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²Nicholas Lemann, *The Promised Land: The Great Black Migration and How It Changed America* (NY: Vintage Books, 1992).

There have been many efforts in the past twenty or thirty years to improve the delivery of health care to minorities. While recognizing that poverty and a lack of health insurance necessarily lead to a crisis among minorities, many of these efforts have concentrated on devising ways to educate African Americans to take advantage of medical services, particularly with regard to preventive care. More recently the creation of the National Center on Minority Health and Health Disparities within the National Institutes of Health and the designation of Healthy People 2010 goals for the nation again have focused renewed attention on these problems. Winston Price, the president of the National Medical Association of black physicians, has advocated outreach efforts to educate people about available health care and help them learn to take care of themselves. He has suggested that doctors take their educational efforts into barber shops, beauty parlors, churches, and community centers.³

Price's suggestions demonstrate an awareness of the importance of community institutions and the role they might play in bringing information to African Americans. This paper will extend this idea and explore the ways in which knowledge of African American history and an understanding of the culture that history developed could contribute to the delivery of health services and help reduce health disparities for minorities. It is important to understand that African Americans have a very long history in America, so long that they were responsible for shaping much of what we consider American culture. In the 340 years after the arrival of Christopher Columbus in the western hemisphere, approximately 10 of the 12 million people who came to the Americas came from Africa.⁴ The first forced migrants from Africa to what became the United States were brought to Virginia in 1619. They were the first of at least twelve generations in slavery in British North America. They experienced over 150 years of slavery before the American Revolution and nearly another 100 years of slavery before it was abolished after the Civil War. After slavery, African Americans suffered another century of discrimination, violence, and segregation before the passage of the modern civil rights legislation.⁵

The story of African Americans is complex. In their history, blacks had a great variety of experiences, and the population was

³"Dying for Basic Care," *Washington Post*, December 21, 2004, F1, c. 1.

⁴George M. Fredrickson, "America's Original Sin," *New York Review of Books*, (March 25, 2004) 34.

⁵James Oliver Horton and Lois E. Horton, *Hard Road to Freedom: The Story of African America* (New Brunswick, New Jersey: Rutgers University Press, 2001).

composed of many different African ethnicities. There were many changes over time, even in the institution of slavery, and the conditions of their lives were subject to regional and class variations. Despite such differences, there are some themes that we can identify to help us understand black history and culture. These themes, along with the strategies that black people developed to cope with hardship, can illuminate how African Americans not only survived, but also how they developed a rich culture, frequently under conditions of extreme deprivation and ruthless oppression. Some of the themes in black history that can help us understand minority health disparities and suggest strategies for care include: threats to cultural survival and uncertainty about the future, threats to the survival of the family, the long history of hard labor, and the subjection to arbitrary authority and arbitrary punishment.

The threat that enslavement posed to the survival of African cultures and the uncertainty about the future that it caused seem obvious. This was especially true of the disruption and hardships caused by the Middle Passage, or the transportation from African to the Americas that characterized the Atlantic slave trade. This trade lasted from the early sixteenth century to the early nineteenth century, when, in 1808, it became illegal, though it was not entirely ended. An estimated 15 million Africans were captured, chained, and tightly packed into cargo holds for the journey. They were packed two deep and, in the most humane calculations, allotted a space one-foot wide by six-feet long for a man, five feet ten inches for a woman, five feet two inches for a boy, and four feet six inches for a girl. These Africans suffered deaths from disease, mistreatment, malnutrition, and suicide. The average death rate on the Middle Passage over the centuries of its existence was 15 percent and sometimes rose to as much as one-third of the cargo.⁶ The psychological suffering caused by the process of enslavement was also great. People were torn from their villages, their families, and their cultural institutions. Often they could not speak the languages of their fellows and suffered fears about the intentions of their captors. Olaudah Equiano was 11 years old when he was captured in West Africa in 1756. He had never seen white people, the ocean, or ships, and could not speak the language of his captors. Observing the “brutally cruel” ways in which these Europeans

⁶James Oliver Horton and Lois E. Horton, *In Hope of Liberty: Culture, Community, and Protest Among Northern Free Blacks, 1700-1860* (NY: Oxford University Press, 1997), 18.

treated each other he was certain he would be mistreated and feared he would be eaten.⁷

In the nineteenth century, after the Atlantic slave trade ended, there was a similar threat to the survival of African American culture. As the Cotton Kingdom expanded into the lower and western South enslaved African Americans were uprooted from long standing coastal communities and shipped or marched to the newly developed plantations. About one million people, often the young and the most able-bodied, were forced into what historian Ira Berlin has called the Second Middle Passage.⁸ Despite these threats to cultural continuity and the hardships of slavery itself African Americans found ways to resist and to preserve important aspects of their cultures. We have evidence that many African languages were in use for at least 200 years, including reports of people speaking their native languages at colonial gatherings at a Philadelphia burial ground and at Congo Square in New Orleans in the early nineteenth century. African religions and tribal practices also survived well into the nineteenth century, as slaves engaged in the ring shout, a form of worship incorporating dance. Some African Muslims also maintained their prayer and burial practices, and some in the nineteenth century could still recite and write passages from the Koran. African Americans also preserved aspects of their cultures by synthesizing African and European languages. For example, the hybrid Gullah still exists today in the Sea Islands of Georgia and South Carolina, and other syncretic forms of Christianity were developed in African American communities.⁹

African Americans managed to preserve aspects of their cultures partly through the networks of communication they developed. These networks relied on slaves and free blacks that had positions that allowed some mobility, such as sailors, river boat workers, and personal servants. These people were among those who carried news and maintained connections between those separated by slavery and the slave trade. Cultures were also preserved in music, through the singing and dancing of worship, through work songs, and the music that formed the basis for the uniquely American blues and jazz. Many cultural values were also preserved in the tradition of storytelling, as in the Brer Rabbit stories that are still a part of American folklore. Africans also preserved parts of their

⁷*The Interesting Narrative of the Life of Olaudah Equiano, or Gustavus Vassa, the African* (1789), reprinted in Arna Bontemps, *Great Slave Narratives* (Boston: Beacon Press, 1969), 28-29.

⁸Ira Berlin, *Generations of Captivity* (Cambridge, Mass.: Harvard University Press, 2003), 162.

⁹Horton and Horton, *In Hope of Liberty*.

medical traditions in America, demonstrating the efficacy of inoculation for smallpox, using herbal remedies, and providing psychological interventions traditionally performed by conjurers. It was common for even whites on large plantations in the South to rely on slave doctors to treat their ailments, and slave midwives delivered the babies of the plantation.¹⁰

Another important theme for understanding both the physical and psychological health of African Americans during the centuries of slavery and beyond to the sharecropping times of Uless Carter is the pervasiveness of hard labor, often coupled with inadequate diet. The coerced hard labor applied equally to men and women in slavery and to children as soon as they were deemed physically able to work. Evidence from the African burial ground used in New York City in the 1700s indicates some of the consequences of physical conditions under which the slaves worked. Archeological analysis of the remains indicates a high mortality for infants and for teenagers. Many of these African slaves suffered from malnutrition that made them vulnerable to anemia and infectious disease. They had broken bones from beatings they suffered and hairline fractures of the neck and shoulders, a consequence of carrying very heavy loads on their heads. Some of the children's remains even had backbones jammed into the braincase, probably as a result of their falling while carrying heavy loads on their heads.¹¹ Hard labor and inadequate diet were the hallmarks of much of black labor from the 1600s until well into the 20th century, causing a long history of the resulting vulnerability to life-threatening diseases.

In the face of such hardships, free black communities from the late eighteenth century on created cooperative organizations. Burial societies maintained African cultural traditions and offered financial resources to continue traditional practices. Mutual aid organizations created pooled resources to pay for funerals; to carry members through periods of sickness, disability, and unemployment; and to care for widows and orphans. These community organizations were especially important because black people were generally excluded from the aid provided by white philanthropic societies and often from government aid as well.¹²

¹⁰Eugene D. Genovese, *Roll, Jordan, Roll: The World the Slaves Made* (NY: Pantheon Books, 1974).

¹¹Steven Mintz, *Huck's Raft: A History of American Childhood* (Cambridge, Mass: Harvard University Press, 2004), 42.

¹²Horton and Horton, *In Hope of Liberty*; James Oliver Horton and Lois E. Horton, *Black Bostonians: Family Life and Community Struggle in the Antebellum North* (NY: Holmes and Meier, 1979, revised edition, 2000).

Through their long history, African Americans have frequently been subject to arbitrary authority often accompanied by arbitrary punishments. They operated from a position of relative powerlessness, as did Uless Carter's sharecropping family, both during slavery and the long post-slavery period. Slaveholders used whippings, maiming, and other tortures and humiliations to enforce their labor demands and maintain control over the slave population. After slavery, southern whites used lynching and other attacks to keep black people from "rising above their station." People could suffer acts of violence for such things as dressing too well, being too successful in business, or even, in the case of black men, being too polite to white women. Small humiliations were an everyday reality, and life-threatening situations a common occurrence. The twentieth century poet, lawyer, and priest Pauli Murray reported that when she was six years old, she saw the body of a man who had been murdered for walking across a white man's watermelon patch.¹³ After the Civil War and through much of the twentieth century, African Americans in the South were forced to the back seats in buses and streetcars; required to attend separate and inferior schools and to use separate water fountains and other public facilities; and denied admission to restaurants, restrooms, and hospital facilities.

Partly as a way to cope with the dangers and humiliations of arbitrary authority, many African Americans found strength in religion. Some were able to deal with their anger through a belief in biblical promises of divine retribution for injustice. The black church provided a refuge from white oversight and control where pride and dignity could be preserved. The church became the crucial center of the black community. When in the 1950s civil rights activists in Montgomery, Alabama organized a boycott to protest the segregation of the buses, they turned to a young minister at the Dexter Avenue Baptist Church. The church became the heart of civil rights organization, and the Reverend Martin Luther King, Jr. was catapulted into national prominence.

Perhaps the most difficult situations that African Americans faced in slavery were threats to the family. The famous black abolitionist Frederick Douglass remembered seeing his mother only a few times when he was an enslaved child. He couldn't remember what she looked like, since he was very young and had seen her only at night. She worked on a different plantation and had to walk the long distance after sundown after she finished her work there and returned early the next morning. Douglass was more fortunate than most slave children because he was cared for by

¹³Mintz, *Huck's Raft*, 116.

his grandmother.¹⁴ Sojourner Truth, black abolitionist and women's rights advocate, was enslaved in New York State when her owner took her five-year-old son Peter from her and gave him as a wedding gift to his daughter. Peter's new owners illegally took him to the South. At his new home, he suffered regular beatings and slept under the front porch every night where his mistress sometimes came to minister to his wounds. When he was finally recovered and returned to New York, he so feared his master's retribution that he refused to recognize his own mother. It was some time before she could reassure him that it was safe for him to be reunited with the broken-hearted and angry Truth.¹⁵

Under such threats, families remained very important to African Americans. As a consequence, one of the most important reasons that enslaved people undertook the arduous and dangerous measure of running away was their desire to see family members from whom they had been separated. Harriet Jacobs, an enslaved woman in nineteenth century North Carolina, was continually harassed by her owner. She took refuge with her grandmother, a free black woman, and spent seven years hiding in an attic garret so that she could remain close to her children before she managed to escape to the North.¹⁶ For many years after the Civil War and the end of slavery, newspapers ran advertisements from people searching for family members lost in slavery.

So many families were broken by slavery that African Americans developed ways of maintaining the emotional resources provided by families. Strong extended family ties helped care for children who lost their parents, as did recreated families where children would be cared for by other unrelated adults who served as "aunts" and "uncles." This phenomenon continued in black communities in the twentieth century with informal adoptions. Such cooperative solutions resulted in the sharing of resources and the networks of rights and obligations that extended from the family to the community. These measures helped people survive in slavery and formed the basis of the underground railroad that allowed some to escape to freedom. In the mid-twentieth century, anthropologist Carol Stack found that such networks among single mothers on welfare helped the women survive with very few individual resources.¹⁷

¹⁴Frederick Douglass, *Narrative of the Life of Frederick Douglass*, edited by David W. Blight (Boston: Bedford Books of St. Martin's Press, 1993).

¹⁵James Oliver Horton and Lois E. Horton, *Slavery and the Making of America* (NY: Oxford University Press, 2005), 76.

¹⁶Harriet Jacobs, *Incidents in the Life of a Slave Girl Written by Herself*, edited by Jean Fagan Yellin (Cambridge, Mass.: Harvard University Press, 1987).

¹⁷Carol B. Stack, *All Our Kin: Strategies for Survival in a Black Community* (NY: Harper & Row, 1975).

What lessons can we learn from this history that might guide us in health education and the provision of health care to African Americans? The themes discussed above suggest some fruitful approaches. African Americans' history of being subjected to arbitrary authority, discrimination, humiliation, and exclusion from facilities indicate the importance of personal contacts and personal testimony in convincing people to use health services and making them amenable to specific treatments. It is not only a matter of making services available, but also a matter of establishing trust in the professionals and the services that are available.

Cooperative or communal approaches to health care provision, rather than individualist approaches, also seem more compatible with the ways that African Americans have historically met individual, family, and community needs. The necessity for poor people to pool resources and the high value placed on commitment to the good of the group suggest enlisting business people, educators, and medical professionals to provide services at least partly as a matter of responsibility to the community. Communal values also suggest that enlisting kinship and community groups would be an effective strategy. Health care providers could work through fraternities, sororities, fraternal organizations, and family reunions to bring information and services to people.

Probably the most important lesson we can learn from African American history concerns the centrality of the church in black communities. In churches, community members of all stations in life maintain personal ties and work under a structure of authority that is democratically organized and highly respected. Knowing this history would indicate that the most effective efforts would take education, health screening and preventive care to the people through the churches. Cooperative efforts by health care professionals, community businesses, and churches may be able to provide clinics for routine care and screening in the churches themselves, addressing many of the problems of accessibility, particularly for poor people who cannot take time off from work and have difficulty getting to doctors' offices. Such efforts would recognize the church as an institution with a very long history of importance to the lives of African American people. Thus, by understanding the long history of blacks in America and the culture that history developed, we can identify the ways that African Americans coped with hardships, survived, and sometimes prospered. Health care providers might use cultural strengths such as strong family ties and active black churches to combat health disparities among people of color.

WEAVING THE TAPESTRY OF HEALTHIER CULTURES

Dr. Gege Dimond
Edited by Lorraine Cronk, MA

Are the health care issues in the United States really so unique that we cannot come up with solutions? There have been many theories and many approaches made to solve the problems—providing what is considered adequate care within acceptable business parameters. Truthfully, there has been a sociological influence on medical reform for years. A review of some of the respected theories in the field reveals the thoroughness that has predicated the proposed solutions.

Khaldun's six principles may be regarded as a pioneering sociological concept, applying those thoughts in the research of organizational management from the viewpoint of humanity. This was great for providing the care, but lacked the stability of the business aspect.

August Comte, known as "the sire of sociology," described not only the basic of a variable structure of society but also the course of human development. Similarly, my own proposal inherently seeks to restructure the delivery of care and requires a deep understanding that change is pervasive and social structure is constantly in flux.

Wilbert Moore, a major scholar of social change, has defined change as the "significant alteration of social structures," meaning social structures to be "the pattern of social action and interaction." There are other definitions of change, such as "variation or modification in any aspect of social process, pattern, or form" and "any modification in established pattern of interhuman relationships and standards of conduct," but all of them seem to have both aspects of structure and/or stability and aspects of instability or flux.

One example of using a people approach of turning an organization around is by Clemens and Maylor quoting Ernest Hemingway in *For Whom the Bell Tolls*. Published in 1940, Hemingway's classic novel demonstrates that people can lead by taking over and turning troubles around. "No man is an island entire of itself, a man is a piece of the continent, a part of the main. If Clod be washed away by the sea, Europe is the less, as well as if a promontory were, as well as if manner their friend or of thine own were. Any man's death demises me, because I am involved in mankind; and therefore never seem to know for whom the bells toll; it tolls for thee."

This leads me then to the beliefs and visions held by Ethel Lund. She told the members of her Tribal Nation that by making the choices they

had or had not made; they had caused the deteriorating effect on themselves and their health. This, of course, was not deliberate or intentional, but rather the result of the influence of governmental control and replacing the natural Tribal homeopathy with the clinical medicine brought by civilization.

Ms. Lund studied the problems that were occurring, analyzed the events and trends of what had happened, and built a strong vision of what was needed for the good of her people. She is both a part of their history and a leader in the Tribal Health Care System. She realized that with the gradual elimination of alternative medical care came the elimination of the patient's role and responsibilities in health care. She knew, if you could identify the prisoners of the system and encourage them to develop their thinking processes, you could change the results and their reality. This conference could be the beginning of just such change.

To create a basis upon which such change can be built perhaps some definitions would be helpful. During my research, I kept hearing such words as disparity and incongruity, so I went to the Webster New World Dictionary to be sure of the definitions: Disparity—unequal, inequality or difference as in rank, amount, quality, etc; unlikeness. Incongruity—the condition or quality of fact of being incongruous; specifically, (A) lack of harmony or agreement or (B) lack of fitness or appropriateness, something incongruous.

Determining the appropriate words while composing these descriptions for this First Annual Winter Institute Conference for Black Studies, it seems clear that solving the disparity would involve responsibility for improved health. That it is a shared one—each one of us must work on our own, but also together with families and communities to eliminate the prevalent incongruities to improve the quality of life for our people. Having said that, we must remember that each and every person is different, one size does not fit all.

Dr. Leo Gallant spent fourteen years in the research of indigenous healers and alternative medicine and found that as much as they differed, they also shared a common theme that divides them from modern, clinical medicine. They all approach sickness as a problem of balance and relationship. They see sickness as the result of disharmony between the sick person and his or her environment, rather than the product of specific disease. Gallant felt that by understanding how the universal wisdom was displaced from the conceptual basis of western medicine, we may learn how to restore its balance. As Kaufman described, "The person who is sick and the web of the relationship of which he is a part."

To do this, we must define our environment and the basis of our

western medicine in the United States. We have, as a nation of color and a global nation, a responsibility to inform and educate our partners, the healers, toward improvements so that we may better work together to foster healthier individual families and communities. This must not focus on one particular need. At this point in the process, the function must be broad, using a philosophy similar to Peter Senges' system thinking, or, if you will, even as a way of reverting to the tribal way of doing things, asking the basic questions:

- How does what we are doing affect the beneficiaries?
- How can we improve?
- Does this theory and philosophy carry over to better community health?

Each community must answer these questions and compile information and potential solutions to the problems in their area. This will build a foundation that will specifically fit the community it will serve. Then, to move toward such a system we need to design and implement a Community Culture Health Board in every community that works closely with the delivery of health care. This will function as a form of preventive medicine, making each facet as functional as possible—this is the most important role we can enact.

The Alaskan tribal people in taking over their own health care system were able to be actively involved in addressing all of the issues and how the issues affect the healing of their people. A great example of this was their ability to have their elders compile information about what the natural native diet would be. After having it analyzed by the Food and Drug Administration, the Alaskan tribal people learned that if the natives had stayed with their own traditional way of eating, they would have had all of the required nutrition to stay healthy. Instead, they had been introduced and encouraged to eat Euro-American food, which we now know can cause diabetes and heart issues, even in children. Also, they were introduced to habits and substances that could cause alcoholism and other health issues they never had before, besides creating a lot of other cultural issues.

The full listing of the steps the tribes took is included here, including specific suggestions for health care providers. Obviously, there is only time for the outline, but comprehensive detail and guidance is available in workshop format and would need to be done in each community. These workshops would ensure maximizing the potential

benefits as well as get things started correctly. The process for building a community-friendly, cost-acceptable health care system is:

- To try to involve citizens in their own health care. This is one of the most important and may be one of the hardest goals to accomplish. This must include all cultural, ethnic, religious, and other diverse groups that will be served by this system.
- To create a Community Health Board to work closely with the delivery of care. This will not only be beneficial to the different cultures, but it will also help the medical faculty. They can use the people on their health board to go back to their community to educate their people about the appropriate way of using the health care system, making it cost effective for everyone. Another benefit is having the people with cultural awareness interact with the other departments, to develop better cooperation between them.

Before any of this can come to pass, however, we have to recognize and learn from our cultural community. In my proposal, I presented an overview of the key steps to follow to make this happen.

So, let us carefully walk through each one of these steps.

- Identify cultural groups—what is your culture?
- What do you know about these cultures?
- What service do you already have in place to meet these needs?
- How can you get patients involved in their own health care?
- Are you aware of their financial issues?
- What other resources or partnerships can you involve?

You will also gain insight into how to move toward these steps by:

- Involving all cultures in their own health care.
- Learning more about other cultures starting with your own.

- Learning the importance of language.
- Asking the right questions and listening to the answers.
- Learning about financial issues.
- Finding the right resources and partnerships.

These key steps have been proven to develop a health care system by eliminating the problems that deny populations the care they need and put care in the hands of consumer friendly corporations, instead of professional individuals and their business oriented care providers. But to make this a win-win situation, we need to stop looking at how the health care community wants to change the cultural community and emphasize what can be learned from them by listening and utilizing the knowledge of centuries so they can help educate their own communities. This would in effect empower the community by enlightening them with knowledge, tradition, and all of the options open to them individually as well as communally.

A PARADIGM SHIFT IN HEALING COMMUNITIES OF COLOR

Chu Chu Onwuachi-Saunders, M.D., M.P.H.

Now more than ever we have an opportunity and duty to propose and support strategies for a health care system that will offer optimal health to all individuals. Optimal health, best defined by the late Dr. John Chissell, is “the best possible emotional, intellectual, physical, spiritual and socio-economic aliveness that one can attain.” It is a continuous process or journey rather than a destination or an end-point.

The conversations continue as to how best use the multidisciplinary skill of allopathetic medicine (conventional/western medicine), traditional practices (indigenous peoples’ therapies) and complementary medicine (a blending of the two), now called Integral Medicine, to provide efficient, effective, and affordable health care for all. The dialogue on this new paradigm of health care is timely, laudable, and forthright. Meanwhile, certain communities within the United States, specifically communities of color, are plagued with increasing health disparities in the face of traditional therapies, complementary or integral medicine, and an evolving conventional health care system.

Communities of color are constantly exposed to a health care system that has not benefited its members. This same health care system fails to understand that multicultural health is the recognition, acceptance, and use of multiple cultures’ health and wellness practices, and not merely offering translation or interpretation of others’ illnesses for alleviation by the dominant society’s therapies. Multicultural health utilizes the knowledge and practices within the individual’s environment to promote healing and, most importantly, to ensure wellness. In the new paradigm of care, multicultural health is timely, morally correct, and a most pertinent answer to the health care dilemma.

Communities of color are often not recognized or acknowledged for their contributions of traditional and indigenous practices and therapies to the global health paradigm and, most recently, to the foundation of integral medicine. Clearly, these same communities have a profound knowledge of psycho-spiritual imbalances that manifest physically as disease or illness. Indigenous societies have known for years that the mind has an effect on the body’s physiological responses and the physical manifestation of illness originates from the mental and/or spiritual realm (the unseen). It is this unseen realm that impacts the physical realm. To maintain the social order within the spiritual realm, an individual should not disrupt his or her harmonic relationship with the divine, the

environment, or themselves—if so, illness will occur. This principle of “total connectedness” becomes the foundation of knowledge for the new paradigm of optimal health/wellness.

Therefore, I propose embracing a new paradigm of health care for communities of color. The concept of complementary/integral medicine offers a real solution—a change in direction and, thus, a focus toward optimal health. Along with positive life choices, integral medicine offers the opportunity and insight needed for healing and sustaining wellness among communities of color within the United States.

One very important or vital ingredient to this new paradigm’s success will be the health care provider—the individual who routinely engages in the practice of restoring or maintaining the health and wellness of individuals through therapies. The recent Institute of Medicine’s report on racial and ethnic health disparities highlighted that health care providers contribute to disparities in health care through bias, stereotyping, prejudice, and clinical uncertainty. The same report also highlighted that providers are a key element to eliminating health disparities. Therefore, these individuals pose a unique role in the problem but an equally pivotal role in the solution.

My father taught me that when you point a finger at someone, three fingers are always pointing back at you. As a health care provider, I, too, have contributed to the dialogue regarding what communities of color should or should not do to ensure wellness and reduce health disparities. Thanks to the wisdom of my elders, I am certain the question is: what will we, as providers, offer this new paradigm that will truly expand opportunities for optimal health and wellness in communities of color? The real question becomes: this time, what will we do differently? The answer is very simple: we become different in our knowledge, behaviors, and attitudes.

A new, insightful health care provider must evolve in order to ensure optimal health and wellness in communities of color. This new provider understands the power of self-reflection in healing and is not afraid to ask, “Who am I and what am I?” In order to effectively heal others, the provider knows he or she must have an understanding of his or her own body, mindset, judgments, biases, and prejudices. This new provider lives in the now and understands the gift of being present. Being fully present allows one’s energy level or vibration to heighten, which in turn enhances one’s ability to heal.

The new provider is a compassionate, empathetic listener who remains self-reflective and acts as a conduit for divine healing. Empathetic listening is healing in itself. These new health care providers

are not afraid to get personal and connected and to become trusted on an intimate level. Their actions and operating styles are deliberately slow-paced and gentle but they also advocate for health and wellness as a human right. They understand their advocacy and positive actions all assist in restoring trust to a fragile health care system.

These new paradigm healers constantly and consistently embrace traditional indigenous therapies that have not been subjected to randomized clinical trials. While conventional or allopathetic practitioners discount such therapies, new providers accept their discomfort with not knowing instead of dismissing or labeling certain therapies as non-scientific or non-evidence-based. These practitioners know how to utilize their intuitiveness and understand its vital role in combination with therapies in the healing process. Additionally, they negate quick fixes in most instances and allow the body to conduct the process of healing slowly and naturally. The new practitioners are reluctant to utilize therapies that only stimulate or suppress. They understand that many pharmaceuticals do not help the body with what it needs in order to heal itself. On the other hand, they acknowledge the use of antibiotics to alleviate critical, acute conditions. These healers of the new millennium do much less dispensing of drugs and far more teaching of prevention, health, and wellness.

These new providers are not afraid to engage in an open dialogue with science and spirituality and, subsequently, are better able to stay in balance and operate from a center of love and compassion while expressing that love freely and openly. These providers see life as a mystery and, rather than trying to explain it, they understand that the knowledge of life is limitless, continually unfolding and that there is always more to explore.

Within this new health care paradigm, this new provider acknowledges that the quality of life is more important than the quantity. This ideal provider recognizes that relationships are all-encompassing, and that through relationships one knows and knowing allows for solutions. The new provider also understands that each patient offers an opportunity for further growth both personally and professionally; thus, the provider engages totally in the overall healing and development and/or maintenance of wellness for every individual.

These providers know that healing is a continuous process of assisting the body with harmony and balance. They know that each disease is not independent, but interdependent. Their patients are not separate from the environments from which they dwell and emerge. Indeed, the most effective practitioners understand that psycho-spiritual

imbalance cannot be measured by any placebo effect and that wellness is actually psycho-spiritual balance within an individual.

This new provider relies on his or her ability to think beyond just “the symptom” and symptom relief. The provider does not evaluate by separating out disease symptoms by differentials, but instead understands that multi-layers of causality affect the various systems within the body. Hence, the provider thinks holistically versus individually and cyclically versus linearly.

In conclusion, these new healers understand the power of the spoken word and love what they do. They know that powerful positive words, thoughts, and actions contribute to the overall healing and wellness process of any community. Many of these aforementioned attributes are often missing within present day allopathetic medicine providers. With time, the philosophy and operating style of the new health care paradigm healer will become the eye on the prize—the opportunity and insight to healing and transforming communities of color.

**THE FUTURE OF HEALTH IN COMMUNITIES OF COLOR
OUT OF MANY, ONE
A MULTICULTURAL ACTION PLAN TO ACHIEVE HEALTH
PARITY**

Ruth T. Perot

I. INTRODUCTION*

Winds of change are stirring and racial and ethnic health disparities have begun to appear on radar screens where policy decisions are made. For the first time ever, government and community leaders have set a date – 2010 – to reach a goal of parity in health.^{1/} The landmark study issued in 2002 by the Institute of Medicine, *Unequal Treatment/Confronting Racial and Ethnic Disparities in Health Care*,^{2/} presents a comparable call for urgent action. Reports released recently by the Agency for Healthcare Research and Quality^{3/} echo similar messages. Racial and ethnic disparities in health persist, their existence is beyond dispute, and they warrant multi-faceted corrective efforts.

African Americans, American Indians and Alaska Natives, Asian Americans, Hispanic/Latino Americans and Native Hawaiians and other Pacific Islanders know their communities – their struggles, hopes, and dreams. Gaps in health status between themselves and the total population have continued for decades, if not for hundreds of years. Representatives of these communities strongly endorse the Institute of Medicine's finding that negative health outcomes associated with these disparities are unacceptable. These representatives know first-hand that living with the *status quo* means dying from preventable causes too soon. For them, inaction must not be an option.

People of color are attaining majority status in states and communities across the nation, and according to the U.S. census, now comprise a third of the U.S. population. New faces and cultures are appearing in communities where they have never been before. Recognition is growing, moreover, that providing *quality* care means responding to racial and ethnic diversity with sensitivity and competence. Further, as cost-effectiveness becomes the watchword, funders are signaling their preference for working coalitions, partnerships, and networks to maximize efforts to tackle common goals.

Underserved racial and ethnic minority groups have responded to these changing realities. They are organizing in neighborhoods, city-wide, across counties, state-wide, and nationally. Tackling health disparities and

expanding access to health care have become common targets for advocacy. People of color are voicing increased demands for services that meet their cultural and language needs. In addition, leaders from communities of color have increasingly embraced collaboration. Some have focused on harmonizing different voices within their communities. Others have joined broad-based coalitions led by non-minority agencies. Still, other people of color have assumed leadership of community networks, in which multiple racial and ethnic groups play a role.

People from diverse communities of color are also turning to *each other* as they focus on shared challenges and the need to mobilize for change. The result is coalitions among communities of color (CACCs.) These coalitions are multicultural, multi-racial, and multi-ethnic. These networks may also be described as racial and ethnic minority coalitions. In these coalitions, persons from diverse groups experiencing disparities provide leadership. These leaders also predominate among coalition participants. Although representatives from non-racial and ethnic minority groups and individuals may be involved, it is clear that they are invited to participate in the CACC in a *supportive*, rather than a leadership role.

Builders of these coalitions have to know the basics. Coalitions of all kinds operate best if certain rules are observed. Demonstrating one's ability to respect and honor other cultures is a "must" in coalition activities of all kinds. Certain communications and group management principles apply no matter who is involved.

At the same time, CACCs are different from other coalitions for many reasons, so experiences with other non-CACC networks do not necessarily transfer. One clear distinction, for example, is this: members of racial and ethnic minority groups share a bond that is linked to their proud histories and common experiences in the U.S. This sharing has given rise to assets for relationship- and coalition-building that are not always valued or even recognized in other kinds of networks. Such coalitions also commonly seek to hasten the day when health parity, equity and wellness become realities in every community.

II. OUT OF MANY, ONE

This presentation describes the coalition-building journey of Out of Many, One (OMO,) a national multi-ethnic/racial network that is committed to the attainment of health parity, equity and justice for all who reside in the U.S. and territories. OMO was created by the five principal communities of color that have experienced disparities. This movement

began in 1999, when Summit Health Institute for Research and Education, Inc. (SHIRE) received a grant from the Office of Minority Health (OMH), U.S. Department of Health and Human Services, to plan and convene a national multicultural conference to advance a Campaign to Eliminate Racial and Ethnic Disparities (CERED). Planning was initiated by a coalition comprising the Asian and Pacific Islander American Health Forum, the Latino Council on Alcohol and Tobacco, the National Indian Council on Aging, Papa Ola Lokahi, and SHIRE. These organizations represent the five primary underserved and uninsured racial and ethnic minorities, which are also identified by the Office of Management and Budget as targeted minority groups in government data gathering and reporting initiatives.

In November 2000, history was made when these five organizations were joined by 75 other organizations, 15 each from Native Hawaiian/other Pacific Islander, Latino/Hispanic, Asian, American Indian/Alaska Native, and African American communities, in a national multicultural working summit. Their task, to create a united health parity agenda, was accomplished in less than two days. Intense and unprecedented multicultural participation and collaboration resulted in the development of a ground-breaking document, *A Multicultural Action Plan to Achieve Health Parity*. This plan was published in its final form by January 31, 2001 and it provides strategic directions for achieving health parity and equal access for communities of color within the next decade (See www.outofmany1.org).

Even more significant, organizations participating in the planning and creative process decided to continue to work together on an ongoing basis under the umbrella of Out of Many, One. OMO emerged and has thrived for five years with the invaluable support and leadership of Hardy Spoehr, the Papa Ola Lokahi staff in Hawaii, and many other organizations. Through our collective efforts, OMO has become established as an advocacy presence in public and private venues and at national and community levels.

OMO's principal goal is to help empower racial and ethnic communities, individually and collectively; to provide leadership to those working toward parity and equity in health; and to promote the attainment of optimal health in all communities. OMO's effective functioning as a multiethnic/racial coalition has also provided guidance for the publication of a handbook on coalition-building, scheduled to be released by the Office of Minority Health in early summer 2005.

III. HIGHLIGHTS OF THE OMO MULTICULTURAL ACTION PLAN

OMO's *Multicultural Action Plan to Achieve Health Parity* makes several important contributions to those who would seek to reshape the future of health in communities of color.

First, the plan articulates a compelling *vision*:

We believe that the attainment of the highest level of health and quality of life is a basic human and civil right. We embrace a vision of healthy communities that respects diverse cultural and spiritual values and empowers all people – individuals and families – in a loving, holistic, healing and compassionate manner. We are committed to develop diverse leadership to build healthy environments and a prosperous, just and humane society.....

Second, the plan places emphasis on *health parity*, a positive concept, which establishes that the parity sought is that consistent with the best level of health achieved by *any* group.

Third, the plan reflects its creators' honest appraisal of the *assets* and *barriers* to working together that must be acknowledged when representatives from different racial and ethnic groups come to the table. Examples of *assets* include:

- Our shared historical bond of commitment to achieve social, racial, economic, environmental justice;
- Our diverse cultural richness of families and communities, spiritual vision, traditions and values;
- Our rapidly growing populations, becoming an emerging majority as a whole; and
- The existence of successful, collaborative, respectful, multicultural networks.

Examples of *barriers* include:

- Lack of access to benefits, infrastructure, capacity;
- Lack of funds and resources;
- Competition for funds;
- Limited number of political advocates; and

- Colonial mentality, internalized/lateralized oppression among ourselves.

Finally, the *Multicultural Action Plan* sets forth a platform with six major goals: 1) achieve universal health care, 2) establish comprehensive health systems, 3) improve cultural, institutional, and educational development, 4) improve research and data, 5) achieve empowerment, and 6) develop community leadership. Each goal is accompanied by specific objectives that have been revisited on a periodic basis as guidance for OMO's strategic planning process.

A review of specific objectives associated with these goals reveals several key points. First, it is clear that OMO is prepared to think and act globally as well as locally. While many of the proposed objectives are community-specific, many call for broad advocacy efforts that impact data and allocation issues and systems of care at the national level. Second, there is a clear emphasis on individual and community self-determination, in such areas as community leadership, consumer rights, and patient care. Third, the collection, reporting, and dissemination of data by ethnicity, race, primary language, and other indicators are seen as essential requirements if health parity is to be attained. Fourth, there is great respect for complementary cultural healing practices and other approaches that recognize the importance of broader, more holistic views of communities of color.

IV. CONCLUSION

I have shared the highlights of a journey of discovery that has widened horizons and deepened relationships among people of color in extraordinary ways. As important, the groundwork has been laid for the creation of a national partnership in which Native Hawaiians, along with other communities of color, are playing a significant leadership role. Out of Many, One will continue its efforts to brighten the future of health in people of color communities -- by thinking strategically, acting effectively, and working collaboratively and harmoniously. We invite your involvement and support as we work to attain the vision of a just and healthy nation and world.

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Y.E.S. 4 HEALTH: A PEER EDUCATION APPROACH TO PREVENTION OF DIABETES IN AFRICAN AMERICAN ADOLESCENTS

*Imani Ma'at
K.A. Harris
G.A. Ogden
P. Rodney*

I. INTRODUCTION

Youth Educational Services 4 Health, Inc. (Y.E.S.) was created in 2002 in response to a need in Atlanta, Georgia where, as in many other cities in the country, chronic diseases are disproportionately impacting African American communities. Major health risks for urban youth and youth of color include: obesity, diabetes (the first Y.E.S. health issue), HIV and other sexually transmitted diseases, teen pregnancy, poor nutrition, substance abuse, smoking, and poor health choices in general. These risks are in part due to lack of information, poor self-esteem, and inadequate community-based health education programs focusing on these important issues (Healthy People 2010). Y.E.S. is a youth-motivated program that seeks to implement and evaluate the effectiveness of teen theater and peer education approaches that inform adolescents about health risk and protective behaviors.

As the rate of preventable disease steadily increases, it is critical to find innovative and effective ways to target adolescents and provide them with information and knowledge that lead to healthy lifestyle choices. One approach that has been successfully utilized globally to engage and educate youth is teen theater and entertainment education. Y.E.S. performs plays on important issues that affect communities of color, such as diabetes. The short-term plan is to perform plays for the greater Atlanta Metropolitan area. Future plans are to take the performances to other states and other countries around the globe.

The leading health indicators and ten major public health issues include several topics that are central to this program: physical activity, overweight and obesity, tobacco use, substance abuse, and responsible sexual behavior. The evolving role of Y.E.S. is tied to addressing the health objectives of the nation with a concentrated look at local youth in the Atlanta Metropolitan Area. Y.E.S. employs new and unique youth-driven approaches to persistent health challenges. Highlighted is the

diabetes project developed by Y.E.S.; however, many health issues will be addressed by Y.E.S. over the continuance of the program.

Diabetes is the sixth leading cause of death in the United States. As of 1999, approximately 16 million Americans – 5.9 percent of the total population – have been diagnosed with diabetes and that number is steadily increasing (AHRQ Fact Sheet, 2001). The disproportionate burden of diabetes on racial and ethnic minorities has been well-documented. Minorities have a higher prevalence of diabetes than whites, and some minorities have higher rates of diabetes-related complications and even death. For example, 10.8 percent of African Americans, 10.6 percent of Mexican Americans, and 9 percent of American Indians have diabetes compared with 6.2 percent of whites (AHRQ Fact Sheet, 2001). In 2001, the diabetes age-adjusted death rate for African Americans was more than twice that for white Americans (49.2 vs. 23.0 per 100,000 population) (CDC, 2004). The rates among most Hispanic Americans are even worse. Among Hispanics/Latinos, the diabetes death rate in 2000 was highest among Puerto Ricans (172 per 100,000), followed by Mexican Americans (122 per 100,000), and Cuban Americans (47 per 100,000) (CDC, 2004).

According to the American Diabetes Association (2005), about 176,500 people less than 20 years of age have diabetes. This represents 0.22 percent of all people in this age group. Obesity and diabetes together cost \$100 billion dollars per year, which is more than the cost of the AIDS epidemic (CDC, 2003). Diabetes is also one of the most common chronic diseases among children in the U.S. About 150,000 young people under the age of 18 – or about one in every 400 -- 500 have diabetes.

There are three main types of diabetes. Type 1 diabetes develops when the body's immune system destroys pancreatic cells that make the hormone insulin, which regulates blood sugar. It normally strikes children and young adults. People with type 1 diabetes must have daily insulin injections to survive. Each year, more than 13,000 young people are diagnosed with type 1 diabetes. Type 2 diabetes begins when the body develops a resistance to insulin and no longer uses the insulin properly. When the body is unable to use the insulin that it makes; the cells of the body cannot use the glucose for energy or fuel (Coleman & Gavin, 2004). As the need for insulin rises, the pancreas gradually loses its ability to produce sufficient amounts of insulin to regulate blood sugar. Previously, type 2 was considered a disease of adults (aged 40 and over) that accounted for 90 -- 95 percent of all diagnosed cases. Now, type 2 is frequently diagnosed among youth of all racial and ethnic groups. Girls are more commonly diagnosed with type 2 diabetes than boys (Fagot-

Campagna, 2000; CDC, 2002). Gestational diabetes, the third type of diabetes, is a form of glucose intolerance diagnosed during pregnancy (Ma'at et al. 2002).

The lack of physical fitness activities for youth is another contributing factor that places teens at increased risk for obesity and diabetes. The level of exercise recommended by the Surgeon General of the U.S. is 30 minutes per day. Recess has been deleted from many school programs in Georgia due to increased violence, safety issues, and the desire to decrease "unstructured time" as a means to increase academic learning (Metzler, 2002). Physical education is no longer a requirement in the public school curriculum in Georgia under House Bill 1187 for grades 6-12 (Metzler, 2002).

Compelling scientific evidence indicates, however, that lifestyle change can prevent or delay the occurrence of type 2 diabetes in high risk groups. This body of evidence from randomized, controlled trials conducted in three countries has definitely established that the maintenance of modest weight loss through diet and physical activity reduces the incidence of type 2 diabetes in high risk persons by about 40 to 60 percent over three to four years (Williamson, et al, 2004).

II. THE Y.E.S. APPROACH

Launched in Dekalb County, Georgia by two friends, Imani Ma'at, Ed.D. and Garry Ogden, Sr., J.D., the mission of Y.E.S is "To provide quality education programs for youth that build self-esteem, knowledge, attitudes, and skills that lead to safe and healthy lifestyle choices." The five components of Y.E.S include: a Teen Theater Program, a Peer Education Program, an International Exchange Program, a Mentoring Program, and a Parents of Teens Program. The first component launched by Y.E.S. was the Teen Theater Program, which aimed to stimulate the talents and heighten the self-esteem of the youth in the program.

The student performers of Y.E.S range in age from 10-18 years. There have been over 50 students involved with Y.E.S since its inception. On average, there are usually 2025 students involved at any given time. There are an equal number of males and females. Students are recruited by friends and word of mouth from local schools and churches.

Y.E.S. has an all-volunteer staff of concerned parents, teachers and public health professionals who embrace the mission and goals of this important program. A sub-set of volunteers have been labeled the Young Adult Mentors (YAMS). These are young African American women; most of them are graduate public health students in Morehouse School of

Medicine's Master of Public Health Program where Imani Ma'at is an Adjunct Assistant Professor. One is a recent graduate of the New York University Master of Public Health Program. All are extremely dedicated and have been valuable assets to the Program. The first choreographer and one of the main characters of the first play, is a very talented young adult male on the maintenance staff of Morehouse School of Medicine.

A. Rehearsals and Performances

Y.E.S. holds rehearsals most Sundays from 2 P.M. to 5 P.M. in donated theatre space at the Horizons High School in Atlanta, Georgia – a high school attended by several Y.E.S. performers. All practice sessions start with warm-up exercises to reinforce the importance of physical fitness. During rehearsals, students work on vocal and acting skills, socialize, and make new friends. Healthy snacks are shared during a ten minute break. Snacks include such items as fruits, nuts, grains, and water. With an open-door policy, guest lectures and performers from the community come to these sessions to provide training and skills that are essential to the students.

III. HISTORY OF PEER-LED HEALTH EDUCATION APPROACHES

Research indicates that peer-driven programs can be more effective in reducing health risk behaviors than teachers or adult-led interventions (Story et. al, 2002). An evaluation of a TEENS study, a peer led nutrition education program, demonstrated that the program was feasible and well-received by youth as an effective way to educate adolescents about appropriate nutrition habits. The TEENS intervention was delivered to a cohort of seventh graders, and again in their eighth year, in which peer leaders assisted in teaching the nutrition curriculum. All sessions involved trained peer educators who assisted teachers and led classroom discussions. The evaluation also revealed that the teens enjoyed the experience and would volunteer to be a peer leader again (Story et. al, 2002). The Y.E.S. experience has shown that teen audiences respond more favorably to their performances than to adult educators providing the same information content using more conventional approaches, such as PowerPoint presentations.

A. Teen Theater/ Entertainment-Education: A Growing Phenomenon in the U.S.

Entertainment education is also known as “edutainment.” Entertainment education uses programs for the radio, theater, music, or television as vehicles to feature socially responsible messages (Glick et. al, 2002). It is the process of purposely designing and implementing a media message both to entertain and educate in order to increase audience members’ knowledge about an educational issue, create favorable attitudes, and change overt behavior. Entertainment education uses the appeal of popular media. The objective is to combine entertainment and education to obtain the best that both have to offer (Singhal & Rogers, 1999).

A current pioneer in this field, Ivan Juzang, founder of MEE (Motivational Educational Entertainment) Productions Inc., uses entertainment education and research-based communication to address health and social issues that impact urban youth. All of the MEE productions have been evaluated using qualitative research methods, primarily focus groups, to measure the impact of the play on targeted audiences. MEE was incorporated in 1990 with the goal of developing research-based, market-driven solutions for issues facing urban and low-income populations living in at-risk environments. MEE is an internationally-recognized communications firm that develops socially-responsible, research-based communication strategies targeting urban and ethnic populations of all ages. Dynamic growth has led to offices in Philadelphia, Washington D.C., Baltimore, and Los Angeles (www.meeproductions.com, 2005).

Besides the work of Juzang of MEE, few evaluations have been conducted on teen theater programs and behavior change in the U.S. (Glick et. al, 2002), which explains that the challenge in effective evaluation in the U.S. is the competition with advanced, highly developed mass media systems. Unlike with many developing countries, the U.S. has to take into account exposure to competing or complementing media messages. Nonetheless, some evaluations on teen theater programs directed at HIV/AIDS and the increase in knowledge regarding HIV/AIDS demonstrate successful results.

Teen theater can have a reciprocal effect as illustrated in the evaluation of the STAR teen theater program in New York City. While research failed to find that the play increased the preventative or health protective behaviors of the cast members, it did increase their knowledge

and awareness about health concerns that were presented in the play (Glick et. al, 2002).

In an evaluation of the New Image Teen Theater in California, researchers found that there was a 21 percent increase in knowledge about contraception from students who saw the play (Glick et. al, 2002).

Teen theater programs and peer-education have been well recognized in the developing world as a creative and effective way to promote behavior change, especially in resource-poor geographic locations. Entertainment-education and peer-led prevention programs have flourished in the U.S. over the past decade (Glick et. al., 2002). Peer-driven initiatives have demonstrated promising results in improving knowledge regarding certain health issues, increasing self-efficacy, and changing attitudes and behaviors. (Story et. al, 2002). This method of prevention is especially popular and effective when targeting adolescents.

The literature successfully documents the effectiveness of peer led interventions and teen theater programs as the best practices for increasing knowledge in adolescent youth. However, in order to mitigate the effects of preventable disease, it is critical to progress from an increase in knowledge to behavior change. More comprehensive research and evaluation methods should measure results in initiating effective behavior change strategies amongst adolescent youth.

In addition, most of teen theater strategies in the U.S. and across the world have focused on sexual and reproductive health issues. The Y.E.S. program is embarking upon fairly new territory in teen theater by focusing on the importance of nutrition and chronic diseases for youth. Y.E.S. can begin to build upon best practices and make sure that research and evaluation techniques effectively measure behavior change. Y.E.S. will bring a new and greatly needed focus to teen theater by concentrating on issues such as chronic diseases that not only affect people of color in the U.S., but also all communities domestically and globally.

IV. THEORETICAL APPROACH

Social Cognitive Theory (SCT) and specifically the tenant of self efficacy are used by Y.E.S in developing the peer education and theater components of its program. According to Bandura (1977), SCT holds that behavior is determined by expectancies and incentives as explained below:

(1) Expectancies:

- Expectancies about environmental clues (that is belief about how events are connected – about what leads to what).
- Expectancies about the consequences of one's own actions (that is, opinions about how individual behavior is likely to influence outcomes). This is termed outcome expectation.
- Expectancies about one's own competence to perform the behavior needed to influence outcomes. This is termed efficacy expectation (i.e., self-efficacy).

(2) Incentives:

- Incentive (or reinforcement) is defined as the value of a particular object or outcome. The outcome may be health status, physical appearance, approval of others, economic gain, or other consequences. Behavior is regulated by its consequences (reinforcements), but only as those consequences are interpreted and understood by the individual (Rosenstock et al., 1988).

Perceived self-efficacy is defined as an individual's perception of his or her ability to demonstrate a particular task based on skill or practice. According to Bandura (1977), self-efficacy (belief in one's ability to perform a behavior) is an important component of SCT. Other concepts include, but are not limited to, the importance of the physical environment, behavioral capability, expectations or anticipatory outcomes of a behavior, and observational learning (Baranowski et al., 2002).

Y.E.S. combines SCT and self-efficacy development with a social determinant of a health approach to change. It is clear that individually-based approaches for health behaviors, such as obesity prevention and treatment, are often viewed as ineffective by themselves because they do not address community, environmental, and systems issues, such as racism, that impact health. Y.E.S. exposes youth to multiple levels of health factors within the community and society in order for them to understand the complexity of influences on health and health outcomes.

V. INTERVENTION/METHOD

A. The Play: A Description

Drive-Thru Justice, an original play written by Imani Ma'at and modified by the group, is about a radical approach created by a small group of concerned African Americans in one community to inform their members about preventable diseases such as diabetes, heart disease, and cancer. This play is an example of the Y.E.S. approach of developing youth-driven intervention strategies that use theater to educate youth about important health issues. Innovative interventions that address the escalating problems of obesity and diabetes among youth of color are critical in mitigating the high incidence rates of diabetes among adolescent youth of color.

Likened to the planning of the Civil Rights Movement launched in the 1960s, the characters purposely purchase a fast-food franchise in order to raise awareness among African Americans, encourage African Americans to take a closer look at poor diet and lifestyle choices, and inspire them to recognize the link between their choices and chronic diseases. The characters denied a randomly selected African American, which happened to be a woman, the fast-food items that she attempted to order for herself and her daughter. The customer sued the franchise, bringing media attention to this very provocative and controversial issue. The media, members of whom were part of the planning committee for the movement, interviewed community members from Brenda's Beauty Salon, a local high school gym class – which just happened to be working on an aerobic dance routine that “rocked the house,” and a Congressional Representative who is later instrumental in securing billions of dollars to increase nutrition and fitness programs nationally.

The characters' plans to raise awareness are ultimately successful, and the community begins to talk about the lawsuit, diabetes, and the risk and protective factors related to this preventable disease. In addition, the play explores the franchise owner's personal struggle and ultimate demise with diabetes. This dramatic play is filled with important educational dialogue about diabetes, (and) laced with humor, music, and dance.

Y.E.S. performed *Drive-Thru Justice* for adolescent and adult audiences at middle schools, churches, and for a Diabetes Awareness Program at the Morehouse School of Medicine. The first performance was for the DeKalb County Schools Food Service Staff at the Lithonia High School. The teens reported anecdotally that they really enjoyed performing

and that it increased their self-confidence and self-esteem. The audience also reported that the play was well-received and individual viewers stated that they would reevaluate the food that they serve in their county's public schools.

B. Research Question

Does the play *Drive-Thru Justice* promote change in knowledge and raise awareness about diabetes among adolescent youth?

This research question was designed to measure the impact that the program has on its audiences, specifically whether the play helps to increase knowledge about diabetes, including the primary risk and protective behaviors related to diabetes. The goal of this intervention is to eventually transform and increase knowledge about diabetes and the importance of a healthy lifestyle into behavior change of audience participants.

VI. RESULTS

The program piloted a pre- and post-test assessment (April 2004) with an audience at the Brown Middle School in Atlanta, Georgia. Results from the five question pre- and post-test survey revealed that prior to the play, 20 out of 46 or 43.5 percent of the audience correctly answered three or more of the questions and eight out of 46 or 17.4 percent correctly answered four or more questions. After viewing the play (two additional participants took the post test) 32 out of 48 or 67 percent correctly answered three or more questions and 17 out of 48 or 35.4 percent correctly answered four or more questions (Table 1). Also, through informal discussions, many Y.E.S. participants indicated that after they had participated for several months, the program increased their self-esteem and self-confidence, some shared information on health with family and friends, and most indicated that they really enjoyed the program. Modest dietary changes were also self-reported by the participants, such as less candy consumption.

Table 1. Change in Diabetes Knowledge after Viewing *Drive-Thru Justice**

#Correct Answers	Pre-Test (n = 46)	Post-Test (n = 48)	% Change
≥3	20 (43.5%)	32 (67%)	+64.9%
≥4	8 (17.4%)	17 (35%)	+49.7%

*These are crude percentages. Demographics were not collected. While most audience members were middle school students, some adults were present and completed surveys.

VII. DISCUSSION

The pilot test evaluation of the play, though rudimentary, was encouraging. Almost immediately after the performance, the Y.E.S. teens soon departed for summer vacation, summer jobs, and were otherwise unavailable during the summer. When they returned in the fall, the group elected to develop a new play on HIV/AIDS issues. There have been numerous requests from the community, however, to perform *Drive-Thru Justice*, so there will be an opportunity to continue the evaluation of the play and its impact on audiences and cast alike. Also, while the youth had expressed a desire to do something new, the untimely and unfortunate death of an adult volunteer/mentor due to complications of diabetes sparked new interest on the part of the teens in revisiting the diabetes play. His passing also reinforced the seriousness of the messages imbedded in the play.

A. Lessons Learned

Countless lessons have been learned. The most significant lesson learned was that programs serving youth have to establish a partnership with parents. Many youth came to Y.E.S. meetings with friends and the organization made the mistake of not contacting parents once their children started attending. While phone calls were made and announcements sent home, many parents did not have knowledge of the vision and mission of the program. This error surfaced as Y.E.S. prepared for its first performance. When scheduling additional rehearsals, one

parent indicated that her son had chores to do and homework and that he was not available for the rehearsals or for the performance. After that experience, which could have crippled the first performance had the organization not had understudies for most of the modules, Y.E.S. held a mandatory meeting of parents to reinforce the goals of the program. Following that meeting, parent participation, cooperation, and flexibility increased substantially.

Also, until recently, participation in Y.E.S. was free of charge. Recently, Y.E.S. management ascertained that a small registration fee (\$50) would be charged in order to add value to the services provided. There was concern that offering the services for free lessened the value of the program. Registration also includes a contract, which delineates membership responsibilities that must be signed by both parents and adolescents.

Another important lesson was the importance of continuing education and training of the youth pertaining to the health issues of concern. Y.E.S. is in the process of developing a curriculum that will be evaluated for effectiveness and for replication if deemed effective. When it first commenced, Y.E.S. held a training retreat in preparation for the performances of *Drive Thru-Justice* at Kennesaw State University. A component of the retreat was a coaching session by a visiting Fulbright Professor of Acting from the Philippines, a Qi Gong instructor, a meditation/self-hypnosis specialist, and others. Due to an open door policy, specialists often visit the rehearsals to enhance the training and skills development of the youth.

Y.E.S. meets on Sundays from 2-5 at the Horizons School in Atlanta. Consistency of the rehearsal schedule has been very important for the youth and parents. Due to travel concerns (students come from all over the Atlanta Metropolitan Area and the public transportation system is not accessible in some areas) problems have arisen on occasion when changes have been made to the schedule.

Y.E.S. has several routine practices; however the program has been able to hold the attention of the teens with special guests, community volunteer work – such as meals on wheels for home-bound residents, and special outings. The attempt has been to make Y.E.S 4 Health a “club” for its students, through which they can sharpen their peer education skills and have fun in the process. Concerning competing interests, it has been the experience of Y.E.S. that the students who join are overcommitted in other activities such as sports, music, student government and theater programs in their schools. We still encourage their participation, but hope that in the future, Y.E.S 4 Health can serve multiple foci for its participants.

Ideally, programs that work with youth to the extent of the Y.E.S. program should provide stipends to support retention. Some of the older students have had to get jobs and eventually stop coming to rehearsals. The payment of stipends will reduce the need to seek outside employment. One of the primary sources of employment for teens is fast-food restaurants. Working in these establishments can potentially reduce the impact of education provided by Y.E.S. on the health benefits of proper nutrition.

Behavior change is a slow process. Anecdotal feedback from the youth of Y.E.S. is encouraging. The youth make small steps in improving their own lifestyle choices while the messages are reinforced consistently through the play rehearsals, training, and discussions. This approach is consistent with Bandura's self-efficacy development theory (1977).

Finally, having a sense of humor, a lot of patience, and as the youth say "keeping it real!" goes a long way when working with youth. Their warmth, laughter, and commitment make it all worthwhile – not to mention their stellar performances and the standing ovations!

There are admittedly days when the generation gap between the adults of the program and the youth seems impracticable. When we reach those thresholds, the YAMs step in and bridge the gap. To them we are grateful. The program exists and persists as a result of the dedication of all involved. It is a long journey, through which we know that we are planting seeds for the future!

VIII. LIMITATIONS

The intervention has not been fully evaluated. The pilot did not include coding of pre- and post-test responses in order to assess change at the individual level. Impact measured by an increase in correct responses was only computed at the group level. There should have also been more questions included in the survey. Five questions are inadequate to assess changes in knowledge with an issue as complex as diabetes. Also, the evaluation would be strengthened if measurements were taken at three and six month intervals after the intervention in order to assess retention of the change in knowledge.

A more in-depth evaluation that measures the impact of the performances on knowledge and attitudes, as well as a process which captures change in knowledge, attitudes, and behaviors of the peer educators of Y.E.S. is needed.

IX. CONCLUSION

The human and economic factors of obesity and diabetes have been astronomical, costing the country billions of dollars per year. This includes direct cost to preventative, diagnostic, and treatment services. The Y.E.S. program is a very economical and feasible intervention, which can reach hundreds of youth at a time. Prevention strategies to educate the public about chronic diseases are primarily focused on adults and not adolescents. They are often in the realm of secondary and tertiary prevention (screening for and managing of disease). Y.E.S. provides an opportunity to invest in youth in the spirit of true primary prevention (preventing diseases from occurring). Y.E.S. builds self-esteem and self-efficacy of the participants by exposing them to training, coaching on important health issues, and having the lessons reinforced through rehearsals and performances. Reinforcement of messages is one of the components of the social cognitive theory to increase self-efficacy. The program also educates teen audiences on those same health issues in a language (that we refer to as “teen-speak”) and format (drama, music, and dance) that is appealing to them. Y.E.S. provides an opportunity for youth to engage in a healthy, informative, and potentially life changing activity, instead of hanging out on the street, watching television, or engaging in premature sexual or other risky health behaviors. This intervention is one way to assist Healthy People 2010 and the Nation in reaching the goal of addressing and eventually controlling this emerging diabetes epidemic among increasing numbers of children and adolescents.

This intervention and evaluation research will greatly benefit the public health and behavioral science community. Y.E.S is an intervention and prevention strategy that is needed to combat the high prevalence and incidence rates of diabetes and other preventable illnesses, and to teach youth important protective behaviors against chronic diseases that they can begin to apply in their daily lives. In addition, this program provides an excellent opportunity to evaluate and document behavior change, particularly in the context of a teen theater approach to this important issue.

The eulogy delivered at the funeral of the Sweet Burger Restaurant in *Drive-Thru Justice* contains the overall message that is conveyed to audiences through this powerful play. Started by the preacher and delivered by the ghost of the character in his own words, the message is that

“Black folks have to have a new relationship with food. Food has always been used to comfort and heal us emotionally while in many cases harming us physically. Diabetes and heart disease are not normal occurrences in life. We continue to develop them through unhealthy lifestyles. We eat poorly and make excuses about exercise. We need to find other ways to show love other than through the cooking of fatty, starchy, sweet, sugary and salty foods. What are we teaching our youth? We have the information and we have the technology – Turn off those televisions! Turn off those video games! Get out and play and run and dance! Eat more vegetables, fruits and grains for a healthier life. Take time to start a garden – even in your apartment if you have to. Live life to the fullest and have fun.”

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