SUMMARY:
For too many racial and ethnic minorities in the U.S., good health care is elusive. Overall health has improved for Americans collectively, yet the prevalence of preventable diseases among racial and ethnic minorities persists. Minorities experience higher rates of preventable disease. Various factors contribute to this disparity. Disparities are the differences in the incidence, prevalence, mortality, and burden of diseases and other adverse conditions that exist among specific population groups in the United States. According to an analysis by the American Journal of Public Health, 886,000 deaths could have been prevented from 1991 to 2000 if African Americans had received the same care as whites, meaning five times as many lives can be saved by correcting the disparities than in developing new treatments.\(^1\) The solution to eliminating racial and ethnic disparities in health is quite simple, yet complex, eliminate poverty and eliminate discrimination. Although there have been advances in human health, the prevalence of preventable diseases among racial and ethnic minorities persists in part to institutional discrimination; yet though advances in science have been made to curb these disparities, genomic sciences, prevention and intervention programs can all aid in closing the disparity gap.

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“Of all the forms of inequality, injustice in health is the most shocking and the most inhumane.”

-Dr. Martin Luther King, Jr.

Health disparities among racial and ethnic groups have a long history and continue to exist in the United States. Although the access to health care was increased with the passage of Medicare and Medicaid in 1965, which attempted to fulfill the need for an adequate primary healthcare delivery system, inequalities are none more apparent than in health. Black beneficiaries are less likely to receive health care services than white beneficiaries; poor, minorities, and young adults continue to be groups most likely to be uninsured. Health status and utilization of health services varies significantly depending upon one’s income, race, and geographic location. The inequality in healthcare is one of the most pressing issues today and for the past two decades there has been increasing attention related to health disparities among racial and ethnic minorities in the United States. In 1985, the Department of Health and Human Services released its report of the Secretary’s Task Force on Black and Minority Health, which revealed significant differences in access to medical care by race and ethnicity within certain disease categories and type of health services. It was the first time a concentrated effort was made to raise the awareness of the health of racial and ethnic minorities in the U.S. and the relative poor health of minority groups compared to the majority white population. The Department of Human Health and Services cogently framed the issue: “despite the unprecedented explosion in scientific knowledge and the phenomenal capacity of medicine to diagnose, treat, and cure disease, Blacks, Hispanics, Native Americans, and those of Asian/Pacific Islander heritage have not benefited fully or equitably from the fruits of science . . .” Since then, in 1998 the Department of Human Health and Services has made it a mission to eliminate health disparities in six health areas by 2010. Although there have been advances in human health, the prevalence of preventable diseases among racial and ethnic minorities persists in part to institutional discrimination; yet though advances in science have been made to curb these disparities, genomic sciences, prevention and intervention programs can all aid in closing the disparity gap.

What is a Disparity

Although the term “disparity” is widely used in public health programs in the U.S., there is a difference of opinion about what is meant by “disparity.” These differing opinions are based on dictionary definitions as well as personal beliefs. What should be agreed upon, however, is that a disparity acts like a signpost indicating that something is wrong. According to the Resource Center for Adolescent Pregnancy Prevention, ETR

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6 Villarruel, Disparities Research: p.4.
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Associates, a private nonprofit health education promotion organization in Santa Cruz, CA, and Carter Pokras & Baquet, health disparities are a chain of events signified by a difference in environment, access to, utilization of, and quality of care, health status or a particular health outcome that deserves scrutiny amongst different groups of people, categorized by gender, race, or ethnicity, education or income, disability, geographic location and sometimes sexual orientation. Furthermore, racial and ethnic health disparities are closely linked to the high rate of preventable chronic disease that many minorities experience. Targeting risk factors or those factors that are not connected to family history or genetics reduces preventable chronic disease, and therefore disparities. However, our health care system itself is deeply biased and the following highlights these prevalent disparities in minority communities.

A Higher Incidence of Disease: Race and Socioeconomic Status

Diabetes is a disease in which the body does not produce or properly use insulin. Insulin is a hormone that is needed to convert sugar, starches and other food into energy needed for daily life. The cause of diabetes continues to be a mystery, although both genetics and environmental factors play a role. Diabetes is currently classified into 4 categories: type 1 diabetes, which is usually diagnosed in childhood or early adulthood; type 2 diabetes, which is diagnosed in middle or old age; gestational diabetes, which occurs during pregnancy, and other, less common types of diabetes that result from genetic defects, drug chemical use, infections, or other diseases. Over the years, diabetes has become a costly disease. One out of every 10 health care dollars spent in the U.S. is related to diabetes with an annual cost of over $132 billion. The U.S. has the largest number of diabetics of all the developed countries. Over the past 40 years, diagnosed and undiagnosed diabetes in the U.S. has increased dramatically and will continue to increase; it is estimated that by 2025, 22 million Americans will have diabetes. Although diabetes is a global epidemic, diabetes is found more rampant in minorities.

In the last 20 years, the issue of health disparities in health between racial and ethnic groups has moved to the forefront of reality and science. Although minorities are much more prone to develop certain diseases than the general population, none more so captures these disparities than diabetes. Diabetes reveals health disparities affecting ethnicity, age, socioeconomic status, sex, and lifestyle, but none more so than the ethnic minority population. Diagnosed diabetes is present in about 7 percent of all adults 45 years and older; however, the rates vary substantially by ethnicity and group.

14 American Diabetes Association, “Diabetes Statistics,” available from: URL:
is especially burdensome among certain groups, particularly African Americans, Hispanic Americans, Native Americans, those of the lower socioeconomic classes, and women. These groups are also least likely to receive timely and adequate health care. Roughly 13 percent of African Americans over 20 years of age suffer from either Type 1 or Type 2 diabetes, one-third of whom are undiagnosed. On average, African Americans are two times more likely to have diabetes than whites of similar age.\(^\text{15}\) Data from the Third National Health and Nutrition Examination Survey and the Hispanic Health and Nutrition Examination Survey indicate that among adults aged 40-74 years, the prevalence of diagnosed diabetes is about 7 percent for non-Hispanic Whites, 12 percent African Americans, and 14 percent both Mexican Americans and Puerto Ricans.\(^\text{16}\) Among the various Asian American and Pacific Islander groups, the rates of diabetes vary substantially but can be as high as 15 percent to 20 percent. The highest rates are experienced by Native American tribes in the Southwest with an estimated prevalence of more than 37 percent.\(^\text{17}\) Moreover, non-White populations also suffer from more frequent complications and greater disease severity. Studies of older adults with diabetes have shown that both Mexican Americans and African Americans experience a greater burden from diabetes than do older non-Hispanic whites. For example, overall age adjusted death rates from diabetes are about 10 percent for non-Hispanic Whites, 20 percent for Hispanic Americans, and 30 percent for African Americans and Native Americans.\(^\text{18}\) A part of the disparity is not only why minorities are more prone to diseases like diabetes, but also why they suffer higher morbidity rates. Calculations show that if health disparities had been eliminated in the last century, there would have been 85,000 fewer black deaths overall in the year 2000, including 22,000 fewer black deaths from diabetes.\(^\text{19}\) These prevalence rates reflect increased mortality among ethnic minorities. Nevertheless, this disparity also affects those with a lower socioeconomic status.

The socially and economically disadvantaged are also at higher risk for diabetes. There is a correlation with the socially and economically disadvantage and the prevalence of this disease and therefore deserves scrutiny. Forty percent of adults with diabetes have less than a high school education, compared with only 20 percent of the general population. Diabetics earn less, with a median individually income of 9,550 compared with 20,125 among non-diabetics. Similarly, whereas the majority of individuals with type 2 diabetes are employed, sizeable proportions are unemployed.\(^\text{20}\) For example, for ages 45-64, 49 percent of diabetics are unemployed, compared with only 28 percent of

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Socioeconomic inequalities in health have attributed to a variety of things that may act as risk factors for diabetes and any other diseases. Social determinants such as poor housing conditions and environmental factors, poor education, nutrition, and health behaviors, and limited access to health care play a major role in health outcomes that members of minority ethnic groups suffer. These disparities, however, would not have existed if it was not for the discrimination in the health care system. Because of the institutional discrimination we see rampant health disparities.

**Institutional Discrimination**

All the research in the world could not eliminate health disparities if we do not address racism and discrimination. Dealing with the prevalent racism and discrimination in health care systems has added burdens that negatively affect health. Discrimination, more specifically institutional discrimination include policies, procedures, and practices that may appear neutral, but the end result is uneven access by group membership to resources, status and power. These policies and practices are part of the history of institutions that have not often been challenged and are accepted as part of the norm. Discrimination within the health care system did not come to prominence until the recent Institute of Medicine Report on unequal treatment, which indicated “racial and ethnic disparities in health care occur in the context of broader historic and contemporary social and economic inequality, and evidence of persistent racial and ethnic discrimination in many sectors of American life.” For example, one area in which discriminatory delivery of health care has been found for both African Americans and Latinos relative to the majority population is the use of analgesic for long bone fractures. In a 1993 study, Hispanics with isolated long-bone fractures were twice as likely as non-Hispanic Whites to receive no pain medication in the emergency department at a major academic medical center in the U.S. A similar study using different methodology at a different medical center showed that black patients had a 66% greater risk than White patients of receiving no analgesic for a long bone fracture. The pervasive discrimination directed toward racial and ethnic minorities in the U.S. requires unique approaches toward eliminating health disparities. One such way, research gathering, has been neglected and avoided among minorities.

Over the years, there have been policy initiatives and recommendations at all levels of government to address disparities among racial and ethnic minorities. One policy initiative, addressing the issue of insufficient data, has played an important role in identifying disparities, but gaps remain and more research must be pursued. A challenge

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27 Ibid.
in conducting health disparity research is the lack of racial and ethnic minority information. It was not until 1985 that the Secretary’s Task Force on Black and Minority Health addressed the issue of insufficient data on racial and ethnic minorities. This report spurred a number of policy initiatives such as developing a policy to ensure the inclusion of racial and ethnic minorities in federally funded research or provide justification as to why they were being excluded. This practice is an example of the institutional discrimination that has existed, which may have very well contributed to the health disparities we see today. Until two decades ago, disparities could not have been addressed because there was no information and research to rely upon. Data is needed to identify and monitor health disparities and consequently, research must be conducted to understand the factors of disparities in health. Not only is there a lack of data because of the purposeful exclusion of minorities, but because there are limited numbers of racial and ethnic minorities who willingly participate in research, mostly attributed to institutional discrimination that has led to mistrust of the system. There needs to be an attempt to correct the imbalance of data and address the mistrust of this discriminatory healthcare system. Many minorities, specifically, African Americans distrust the system because of past experiences:

Recent analyses of the relationship of minority patients with their physicians have demonstrated that provider racism and patient awareness of invidious past events such as the experimentation on slaves and the Tuskegee syphilis experiment have contributed to minority patients having less access to and knowledge of specific medical treatments than their white counterparts, lower levels of trust, and greater unwillingness to participate in clinical trials.

When people experience discrimination in the health care system they will be less likely to place trust in their medical care. Not only do these people lose once by not receiving the care they need, but they also lose in the long run because they will be less willing to participate in health research that could provide the key information to address the disparities they are currently experiencing. Thus, minorities are placed at a disadvantage not only in receiving preventive care, but also in access to newer technology and treatment. Regaining the trust of not only African American patients, but other ethnic minorities at all points of entry to the healthcare system is imperative if we are to reduce health disparities. Though there exists institutional discrimination in the health care system, there have been major advances in health care that can play a role in eliminating disparities among groups of people. It remains to be seen to what degree changes in our health care system and the process of health care delivery can rectify these glaring inequalities, but research can play an important role in not only identifying disparities, but also in designing and testing interventions aimed toward their elimination.

**Genetic Information**

The establishment of the Human Genome Project established a major scientific revolution. Officially launched in 1990 as an international effort, the Human Genome

30 Green, *Human Face*: 303.
Project (HGP) was coordinated in the United States by the National Human Genome Research Institute and the U.S. Department of Energy. Its goal was the complete mapping and understanding of all the genes of a human being. Since that time, a comprehensive sequence of the human genome has been defined. This knowledge contributed to new understanding of biological processes in inherited and chronic diseases, introducing genetic testing into health care and changing ways in which diseases are diagnosed and treated through improved understanding of biology. Referred to as genetic information, it can often be used to indicate the risk for disease based on family history or results of laboratory tests identifying specific changes in chromosomes, DNA, or RNA. Genetic information can be used to address the health disparities, specifically identifying the increase disease rates among minorities obtained through identification of an individual’s genetic information. As the body of knowledge regarding genetic and other factors increases, healthcare providers can and are expected to integrate genomic information about individuals into clinical decision making.

Any two individuals differ in their genetic makeup by only about 0.1 percent. Characterizing this small, yet big difference is one of the most pressing goals for scientists who are trying to discover the influence of genes on human health and disease. Advances in public health are expected to result from understanding variations that make humans different from one another in their vulnerability to disease. Advances in public health and medicine will be possible if it is known where variations lie, how these differ between healthy and sick people, and how individuals with particular variants of DNA are affected by environmental factors. Many of the common diseases that affect the U.S. population, however, are complex and consist of multiple genes and environmental factors, factors in the physical environment as well as the behavioral and social environments.

Genetic testing covers an array of techniques including analysis of human DNA, RNA or proteins. Genetic tests are used as a health care tool to detect gene variants associated with a specific disease or condition. The following are different tools within genetic testing that can be used to combat higher incidence of disease. Diagnostic testing, confirms a diagnosis when a person has signs or symptoms of a genetic disease. The genetic test used depends on the disease for which a person is tested. For example, if a patient has physical features that suggest Down syndrome, a chromosomal test is used.

33 Ibid.
35 Report of the Secretary’s Advisory Committee on Genetics, Health, and Society, Available at: URL: http://www4.od.nih.gov/oba/sacghs/reports/SACGHS_LPS_report.pdf [cited 12 April 2007]
37 Report of the Secretary’s Advisory Committee on Genetics, Health, and Society, Available at: URL: http://www4.od.nih.gov/oba/sacghs/reports/SACGHS_LPS_report.pdf [cited 12 April 2007]
38 National Human Genome Research Institute, “What are Reasons to get Different Types of Genetic Tests,” Available at: URL: <http://genome.gov/19516567#2> [cited 26 May 2007].
Predictive testing can show which people have a higher chance of getting a disease before symptoms appear. For example, one type of predictive test screens for inherited disposition to certain cancers, such as colon and breast cancer. This may be beneficial in curbing health disparities since minority individuals are much more likely to develop and die from cancer than the general U.S. population. Such tests may help by being a part of a better target disease intervention program for those most vulnerable and at risk. Carrier testing can tell individuals if they are carriers of a gene alteration for a type of inherited disorder. Often, but not always, a person who has only one altered copy of a gene for a disorder is called a carrier. Carriers do not have the disease, but can pass on the alteration to their children. If both parents are carriers, their children might inherit an alteration from each parent and get the disease. Examples of this type of disorder are cystic fibrosis and Tay-Sachs. Genetic tests have been helpful in determining whether a certain person is a carrier and have been successful in eliminating Tay-Sachs among the Jewish population. Presymptomatic testing shows which family members are at risk for a certain genetic condition. This type of testing is done with people who do not have symptoms when the alteration causing disease in the family is known. For some diseases, this type of testing can lead to prevention or treatment options. For example, when a disease-causing alteration is found in a family, testing is recommended for all close blood relatives. People in families at high risk for a genetic disease have to live with uncertainty about their future and their children's future. A genetic test result that can show that a known alteration causing disease is not present in a person can provide a sense of relief. Thus, genetic tests may help expectant parents know whether an unborn child will have a genetic condition. This is called prenatal testing or screening. Such tests can screen newborn infants for abnormal or missing proteins that can cause disease.

Through the adoption of these efficacious tests, genetic testing has the ability to prevent or ameliorate adverse health outcomes such as mortality, morbidity, or disability. More research and funding can lead to innovative technologies so that in a few years the sequencing of a patient's entire genome will be an affordable standard diagnostic tool used in health care. Genetic information provides individuals with a better understanding of their own prognosis, risk, or susceptibility to disease, or that of family members to disease. The ability to understand the cause or diagnosis of a disease or to predict the risk of developing a disease at a later time may be viewed by many people as important benefits even in the absence of specific interventions. Test results might lead a person to take steps to lower their chance of disease. This information can also help people to make informed choices about their future. For example, someone could screen for the disease or could make changes to their health habits like diet and exercise. As the number of tests continues to rise, their use in the health care setting is becoming more commonplace. The health care system has not fully resolved its ethical challenges and therefore will make it likely that people with genomic-related health concerns experience

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40 National Human Genome Research Institute, “What are Reasons to get Different Types of Genetic Tests, Available at: URL: <http://genome.gov/19516567#2> [cited 26 May 2007].
41 Ibid.
discriminatory practices. Those who already experience such discrimination may be more at risk in achieving equality within the health care system.

**Protecting Against Genetic Discrimination**

While most Americans are optimistic about the use of genetic information to improve health, many are concerned that genetic information may lead to a loss of societal benefits, such as employment or insurability. People are worried that some insurers may choose not to insure people who are healthy, but genetically pre-disposed to future disease onset. According to insurance companies, such people incur more health-related costs for them than individuals who are not predisposed. Similarly, they fear that some employers might only employ or retain individuals who are not pre-disposed to future disease onset, since healthy individuals are more productive. This type of genetic discrimination will lead to a higher proportion of minorities unable to attain health care.

Because access to health care in the U.S. is complicated by the private healthcare system, in which health care is not a universal benefit, and requires the ability to purchase these services, health disparities already seen may grow wider. In a study of U.S. women at risk to have a mutation in a gene for breast cancer, 55% cited fear of life insurance discrimination as a moderate or important factor in their testing decision. Thus, there may be people not taking advantage of genetic information for the fear that the presence of genetic information on the person’s medical record, such as a gene mutation for an adult onset cancer, may lead to the inability to obtain health insurance. This fear may lead to higher mortality and morbidity rates, because access to health care may be unaffordable because of high prices set by insurance companies. Either way, minority groups are most to be affected since they are already facing these disparities. Thus, when anticipation of the disease becomes reality, a person’s life might be heavily influenced by governmental or institutional policies, not only regarding health, but also education, employment, discrimination, and social care.

Many lawmakers, scientists and health advocacy groups believe that there is a need for federal legislation to prevent genetic discrimination. The Genetic Nondiscrimination Act of 2007 was passed in the U.S. House of Representatives, by a vote of 420-3. The Act makes it an unlawful employment practice for an employer, employment agency, labor organization, or training program to discriminate against an individual or deprive such individual of employment opportunities because of genetic information. It also prohibits the collection and disclosure of genetic information, with certain exceptions and extends medical privacy and confidentiality rules to the disclosure of genetic information. Moreover, it establishes a Genetic Nondiscrimination Study Commission to review the developing science of genetics and advise Congress on the advisability of providing for a disparate impact cause of action under this Act. The Act will protect individuals against discrimination based on their genetic information when it comes to health insurance and employment. These protections are intended to encourage Americans to take advantage of genetic testing as part of their medical care and therefore aid in eliminating disparities. Genetic testing may lead to incremental population health

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44 National Human Genome Research Institute, “Ethics and Policies,” Available at: URL: [http://genome.gov/Pages/PolicyEthics/GeneticDiscrimination/SAPonHR493.pdf](http://genome.gov/Pages/PolicyEthics/GeneticDiscrimination/SAPonHR493.pdf) [cited 27 May 2007].
benefit. But if interventions are designed that are more effective for people with particular genotypes and these people are more compliant in the uptake of interventions, then eliminating disparities becomes a stronger possibility.

**Intervention and Prevention**

New technology, such as genetic testing, is just a tool in eliminating health disparities, but alone will do nothing. Similarly, providing health access to racial and ethnic minorities would decrease the disparity of access and increase the opportunity for quality health care. But while creating a health care system that guarantees affordable coverage to everyone is fundamental to reducing health disparities, the prevention of negative health behaviors that inhibit chronic conditions is also effective since nearly 50 percent of morbidity and mortality is caused by an unhealthy lifestyle.\(^{45}\) Thus, instead of a one size fits all intervention strategy, enhancing the effectiveness of community interventions allows for interventions to be modified to the unique needs and cultures of communities; tailoring community interventions to specific racial and ethnic groups have been effective in altering risky health behaviors.\(^{46}\) A comprehensive community intervention system can influence individual behaviors on a large scale throughout populations and can shift the distribution of risk. For example, the office of Minority Health of the DHHS runs two grant programs focused on reducing racial and ethnic disparities, one is the community programs to improve minority health. The purpose of such programs is to improve the health status of targeted minority populations through health promotion and disease risk reduction intervention programs.\(^{47}\) Programs aim to grant funding to private, non-profit community based, and minority serving organizations. This type of community intervention will have the best chance for success since all levels of the community will be involved in eliminating disparities. Funds are to be used to conduct collaborative efforts to modify behavioral conditions that are often implicated in the health problems of minority groups such as cardiovascular disease.\(^{48}\)

Recognizing the culturally and linguistic diversity of their own population, local organizations, often are better equipped to effectively administer behavioral interventions, and are more likely to be able to surpass cultural and discriminatory barriers. Additionally, these interventions are often administered by community organizations and agencies that have an existing relationship with the populations they are trying to serve. Empirical evidence of community-level intervention shows that efforts to organize communities, educate populations through mass and direct education, provide individuals with screenings for risk factors and change community environments by developing and implementing local programs and policies are effectively altering risky health behaviors.\(^{49}\) Any intervention that is directed at making individuals change behaviors must adjust to the individual’s readiness for change and the cultural norms of the individuals’ and communities. That is why tailoring community interventions to the individuals’ are effective. Programs to improve minority health are demonstrably

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\(^{47}\) Ibid.


\(^{49}\) Ibid.
effective in altering risky health behaviors. Furthermore the programs demonstrate that tailoring interventions to a specific subpopulation is an effective way of reaching a cultural race and or ethnic subpopulation and therefore, a valuable way to eliminate disparities.

**Conclusion**

Minorities experience higher rates of preventable disease. Various factors contribute to this inequity. According to an analysis by the American Journal of Public Health, 886,000 deaths could have been prevented from 1991 to 2000 if African Americans had received the same care as whites, meaning five times as many lives can be saved by correcting the disparities than in developing new treatments.\(^{50}\) The solution to eliminating racial and ethnic disparities in health is quite simple, yet complex, eliminate poverty and eliminate discrimination. The enormity of this task is overwhelming and in fact, may not be accomplished by one strategy or be resolved in a single lifetime. It is important as we move forward that we recognize that racial and ethnic disparities in health care are not caused by individual behavior alone, but individuals can be proactive in regards to their health. Community interventions that focus on preventing disease through altering behaviors are effective in reducing health disparities. These interventions empower individuals to take charge of modifiable aspects of their health. Community interventions tailored to meet specific cultural, racial, or ethnic needs will go a long way in reducing health disparities. Nevertheless, we must recognize the pervasive discrimination in our society that exists for members of racial and ethnic groups. We have a responsibility as a collective society to work in addressing all forms of inequality, but especially those in health. These efforts, while difficult, can only benefit us as a society. Ultimately these programs will ensure that race and ethnicity do not play definitive roles in individual’s health outcomes.

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