

Vernellia R. Randall, Slavery, Segregation and Racism: Trusting the Health Care System Ain't Always Easy! An African American Perspective on Bioethics, 15 Saint Louis University Public Law Review 191 (1996)

Bioethics and Law Symposium Deconstructing Traditional Paradigms in Bioethics: Race, Gender, Class, and Culture Copyright (c) 1996 by the St. Louis University School of Law; Vernellia R. Randall

I am a registered nurse and a family nurse practitioner. I have a master's degree in nursing. I practiced nursing for 15 years in Alaska and Washington. I write and work in the area of health care law. I understand the health care system and the legal system . . . I am African American and trust the health care system to work in ways that ultimately will harm my people. [FN]1

I. Introduction

Many people are surprised at the level of distrust of the health care system held by African Americans. However, fear and distrust of the health care system is a natural and logical response to the history of experimentation and abuse. The fear and distrust shape our lives and, consequently, our perspectives. [FN]2 That perspective keeps African Americans from getting health care treatment, from participating in medical research, from signing living wills, and from donating organs. That perspective affects the health care that African Americans receive. This fear and distrust is rarely acknowledged in traditional bioethical discourse.

Some bioethicists question the existence of a “uniquely” African American bioethical perspective. [FN]3 They maintain that since the values and beliefs held by African Americans are also held by other oppressed groups, such as Native Americans, there is no African American perspective. However, these traditional bioethicists miss (or ignore) an important point: perspective is merely a subjective evaluation of the relative significance of something--a point-of-view. [FN]4 Thus, to acknowledge an African American perspective, it is not necessary that African American values and belief systems be entirely different from others.

It is faulty to assume that any group shares exactly the same value system with other groups. For example, Americans do not have one ethical perspective. Rather, race, class, and gender modify the commonality of the American experience. Different groups have had different experiences that, at a minimum, modify the dominant American perspective, if not replace it with an entirely different value structure. For African Americans, the combination of slavery, segregation, and racism have given us a different set of “intervening background assumptions about such essential bioethical concepts as personhood, bodily integrity, the moral community, fulfilling lives and utility.” [FN]5

*193 As a subculture of the American society, we have experienced something that others have

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not. The unique combination of slavery, segregation, and racism have caused us to develop not only different behavioral patterns, values, and beliefs but also different definitions, standards, or ordering of values. Furthermore, even where there is little difference in value systems and perspectives, there is a difference in the normative application of bioethical principles. For instance, there is no question that the principles of autonomy, beneficence, nonmaleficence, and justice have not been applied to African Americans in the same manner as European Americans.

In the "Poplar Tree Narrative" Dr. Dick, a conscientious physician, applies the prima facie principles of beneficence, autonomy, and justice in such a way that castration of his black male patient is construed as a morally justifiable act, in substance and as a procedure [It kept the male] from getting into "trouble" [It made the male] . . . a better slave. . . . [He protected the male patient's autonomy] by getting what he construes to be [the patient's] informed consent. [FN]6

The apparent principles of Eurocentric bioethics are "embedded in a cultural matrix that encodes them with meaning." [FN]7 The reality of bioethics is that ideas, such as autonomy, choice, beneficence, justice, and informed *194 consent, are grounded in perspective and cultural context. [FN]8 Perspectives are based, in part, on class, race, and gender experiences. The experiences of poor people are different from those of rich people; those of African Americans are different from European Americans, Native Americans, Hispanic Americans or Asian Americans. Experiences differ for women and men. Furthermore, rich people, White people, and men have more power than poor people, African Americans, or women. Power also affects experiences. A group's perspective reflects both cultural context and power or status differentials. [FN]9

But what then forms the basis of the African American perspective? [FN]10 Certainly, African American culture has acquired a significant part of its roots from the continent of Africa. For us, that means a belief system that includes a humanistic orientation, [FN]11 a focus on both personal and social responsibilities, [FN]12 and a high value placed on community belonging. [FN]13 To the extent that bioethical discourse and practice do not incorporate these values, they do not reflect the values of the African American community. [FN]14

However, African Americans' distrust of the health care system is based on more than a lack of certain African-based values. Our distrust is the direct result of our unique cultural birth in America. The African American culture is uniquely American. In some ways, African Americans, like Indians and *195 Eskimos, are native Americans; that is, as a culture, African Americans exist only in America. African Americans are a blend of all the races of the world. [FN]15 The dominant racial basis for our group is a blend of features from many African tribes. The most prominent influence on African American culture has been its past (and present) experiences of slavery, segregation, and racism. These African American experiences are clear evidence of cultural context, power, and status differentials which have resulted in a distrust of

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the health care system. This historical distrust is reinforced through current, continued, and ever-present institutional racism. [FN]16 These experiences fuel the basis for African American distrust. [FN]17

II. The Basis for African American Distrust

African Americans' distrust of the health care system is built out of a history that includes experimentation, the Sickle Cell Screening Initiative, Family Planning/Involuntary Sterilization, and the participation of the medical system in the justification of racism and discrimination in society. [FN]18

A. Experimentation and Teaching Materials

The distrust of the American health care system is grounded in the knowledge that the health care system has been built on bodies of African Americans. For instance, the nineteenth century marked the rise of modern U.S. medicine. The advances in medicine were legion:

Advances in basic sciences such as pathology, histology, physiology and pharmacology; the introduction of the statistics and the numerical methods which forever changed the nature and scope of clinical medicine and public health; the clinical acceptance of vaccination for smallpox; introduction of the stethoscope; . . . controlling puerperal fever; rapid advances in clinical schools . . . laboratory medicine . . . and publication of Percival's Code of Medical Ethics. [FN]19

However, during the same period the American health care system *196 evidenced a lack of attachment to esoteric research and pure science that resulted in American physicians performing “bold, occasionally brilliant, clinical medical feats which were not being performed anywhere else on earth.” [FN]20 Then and today it seems to be of little importance that those “bold, occasionally brilliant . . . medical feats” occurred on Blacks and the poor. Understanding the extent of the experimentation is important for understanding the basis of the distrust of African Americans. Slaves served both as instructional material for teaching medical students and as a source of entertainment at medical conventions. [FN]21 For instance, enslaved albinos and Siamese twins were often displayed at medical society meetings as freaks and sports. [FN]22

1. Experimentation During Slavery

In the 1800s, Dr. McDowell successfully performed the removal of an ovarian tumor, a dangerous and radical surgery which he perfected on slaves. [FN]23 In 1800, hundreds of slaves, including two hundred slaves of Thomas Jefferson, were inoculated with smallpox to test the safety of a new vaccine. [FN]24 Dr. Crawford Long, probably the first physician to use

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ether agent as a general anesthetic, conducted a large percentage of his early experiments on slaves. [FN]25 To determine which medication would allow a person to withstand high temperatures, Dr. Thomas Hamilton placed slaves in an open-pit oven which was constructed to contain heat with only the slaves' heads above *197 ground. [FN]26 Dr. Walter F. Jones used a group of slaves to test a remedy for typhoid pneumonia which involved pouring five gallons of boiling water on the spinal column. [FN]27 Slaves actually suspected physicians of killing slaves or letting them die for purposes of dissection. [FN]28 While these rumors were never documented, slaves' bodies were dug up and sold to medical schools. [FN]29 Dr. Alexander Somervail, after accidentally discovering how to relieve the suppression of urine, tested his theory on other Black patients. [FN]30 Robert Jennings is credited with the development of a successful vaccination against typhoid infection that resulted from his successful experimentation on thirty slaves and free Blacks. [FN]31 Dr. P.C. Spencer, who gained notoriety with his discovery of an efficient and relatively safe technique for treating painful bladder stones, perfected his technique by performing the painful experimental surgery on slaves. [FN]32 Dr. Marion Sims--considered the father of gynecological surgery--perfected the techniques for gynecological surgery on slaves. [FN]33 He addicted the women to narcotics in order to sedate and immobilize them post-operatively. [FN]34 Furthermore, he performed the surgery repeatedly on the same women. [FN]35 Though the social norms have changed dramatically, Sims is still revered as a hero and an icon; the complete picture of him as a person who abused and exploited slaves is usually never portrayed. [FN]36

2. Post-slavery Experimentation

The most well known post-slavery experiment is the Tuskegee Syphilis *198 Experiment which the United States engineered from 1932 through 1972. [FN]37 The Tuskegee Experiment involved four hundred African American men in a government-sponsored study to research the effects of untreated syphilis. [FN]38 While the men were not deliberately exposed to syphilis, as some rumors maintained, they were never told that they were not being treated or that effective treatment was available. [FN]39 Furthermore, even though the experiment was regularly reported over the course of the forty years, there was no outcry from the medical establishment. [FN]40 The effects of the Tuskegee Syphilis Experiment of maintaining and strengthening the distrust in the health care system can not be underestimated. The Tuskegee study served to reinforce the belief in the African American community that the distrust of the medical system was not merely an historical issue. [FN]41

The Tuskegee Syphilis Experiment is not the only evidence of post-slavery abuse. In 1963, the United States Public Health Service, the American Cancer Society, and the Jewish Chronic Disease Hospital of Brooklyn, New York, participated in an experiment in which three physicians injected live cancer cells into twenty-two chronically ill and debilitated African American patients. [FN]42 The patients did not consent, nor were they aware that they were being injected with these cells. [FN]43 In 1972, twenty women, primarily poor, young, and

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Black, were bused from Chicago to Philadelphia to receive *199 abortions in an outpatient clinic where a new experimental medical device, called the Super Coil, was being used to induce the abortion. [FN]44 A complication of using Super Coil was uncontrollable bleeding that would eventually lead to shock and would require a total abdominal hysterectomy. [FN]45 During the 1970s, the government collected blood samples from seven thousand Black youths. Parents were told that their children were being tested for anemia, but instead, the government was looking for signs that the children were genetically predisposed to criminal activity. [FN]46 A similar experiment was performed on six thousand young men--approximately 85 percent of whom were Black--housed in Maryland state institutions for abandoned or delinquent children. [FN]47 The children's confidentiality was not protected and the blood-test results were passed to the courts to use as they saw fit. [FN]48 At least eighty-two charity patients were exposed to full-body radiation at the University of Cincinnati Medical Center. [FN]49 The patients were exposed to radiation ten times the level believed to be safe at the time; twenty-five patients died. Three-quarters of the patients in the study were Black men and women. The consent signatures were forged. [FN]50 Many women of color have been sterilized without their informed consent so that medical residents could gain additional experience in performing tubal ligations and hysterectomies. [FN]51

3. Prison and Military Abuse

One area of significant post-slavery abuse has been the experimentation that has occurred in prisons. Because African Americans make up forty-four percent of all prisoners--almost four times our proportion in the general population-- we are overrepresented in any prison abuse. [FN]52 In 1962, at least 396 inmates at the Ohio State Prison were injected with live cancer cells so *200 researchers could study the progression of the disease. [FN]53 Between 1963 and 1971, radioactive thymidine, a genetic compound, was injected into the testicles of more than one hundred prisoners at the Oregon State Penitentiary to see whether the rate of sperm production was affected by exposure to steroidal hormones. [FN]54 Throughout Alabama between 1967 and 1969, inmates were used in flawed blood plasma trials. The study was managed by Dr. Austin R. Stough at Kilby, Draper, and McAlester prisons. There was no informed consent, and no accurate records were kept. [FN]55 At a California medical facility between 1967 and 1968, prisoners were paralyzed with succinylcholine, a neuromuscular compound. Because their breathing capacity was shut down, many likened the experience to drowning. When five of the sixty-four prisoners refused to participate in the experiment, the institution's special treatment board gave "permission" for prisoners to be injected against their will. [FN]56 In 1990, 1.7 million soldiers--twenty-two percent of whom were Black--were forced to take experimental vaccines under federal law. The law stipulates that soldiers cannot refuse to participate in the government's medical experiments. [FN]57

The above instances of slavery and post-slavery abuses are cited not because they are the only instances of experimentation and abuse of African Americans, but because they are some of the

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most famous. [FN]58 While many Blacks may not be able to give you the details of the experimentation and abuse, the instances are a part of the collective Black consciousness which still influence African Americans' reaction to the health care system.

B. Sickle-Cell Screening

The debacle of sickle-cell screening in the 1970s also increased the distrust of the medical system, as did medical experimentation. [FN]59 Although sickle-cell disease has been described since 1910, it did not become a priority for federal *201 or private funding until the 1970s. [FN]60 In the 1970s, large scale screening was undertaken with the goal of changing African American mating behavior. [FN]61 Unfortunately, the initiative promoted confusion regarding the difference between carriers and those with the disease. [FN]62 This confusion resulted in widespread discrimination against African Americans. [FN]63 Some states passed legislation requiring all African American children entering school to be screened for the sickle-cell trait, even though there was no treatment or cure for the sickle-cell disease. [FN]64 Some states required prisoners to be tested, even though there would be no opportunity for them to pass on the trait. [FN]65 Job and insurance discrimination were both real and attempted. [FN]66 The military considered banning all African Americans from the armed services. African American airline stewardesses were fired. Insurance rates went up for carriers. Some companies refused to insure carriers. [FN]67 During that period, many African Americans came to believe that the sickle-cell screening initiative was merely a disguised genocide attempt, since often the only advice given to African Americans with the trait was, "Don't have kids." [FN]68

***202 C. Family Planning and Involuntary Sterilization**

Family planning initiatives have been described as another attempt to reduce the Black population. [FN]69 This view is not without credibility. The fact is that the historical roots of family planning and birth control have been centered in controlling the population growth of African Americans. Margaret Sanger, considered the "mother of family planning and reproductive freedom," supported and promoted the use of reproductive technology to diminish the reproductive liberty of African Americans. [FN]70

We do not want word to go out that we want to exterminate the Negro population and the [Negro] minister is the man who can straighten out that idea if it ever occurs to any of their more rebellious members. [FN]71

Throughout United States history, family planning and birth control have been used to limit the population size of African Americans. In the 1930s, the government funded the first birth control clinics as a way of lowering the Black birthrate:

In 1939, the Birth Control Federation of America planned a "Negro Project" designed to limit

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reproduction by blacks who “still breed carelessly and disastrously, with the result that the increase among Negroes, even more than among whites, is from that portion of the population least intelligent and fit, and least able to rear children properly.” [FN]72

In fact, the early birth control movement included strong factions advocating *203 eugenics or compulsory sterilization. [FN]73

In the 1960s, the government expanded the subsidization of family planning clinics as a way to reduce the number of persons on welfare. [FN]74 In so doing, the number of clinics were proportional to the number of Blacks and Hispanics in a community. [FN]75

In the 1970s, some doctors would only deliver babies or perform abortions on pregnant African American women if the women consented to sterilization. [FN]76 Other women were threatened with the withdrawal of their welfare benefits if they did not agree to sterilization. [FN]77 In a case brought by poor teenage African American women in Alabama, a federal district court found that an estimated 100,000 to 150,000 poor women were sterilized annually under federally funded programs. [FN]78 In the 1970s and 1980s, Public Assistance officials tricked African American welfare recipients into having their teenage daughters sterilized. [FN]79

A 1982 study determined that only twenty-five percent of White women were sterilized, compared to thirty-four percent of African American women. [FN]80 African American women of all marital statuses were more likely than White women to use sterilization as a contraceptive method. [FN]81 Further, African Americans in the South have the highest rates of hysterectomy and tubal ligation in the United States. [FN]82

Today, some individual doctors encourage African American women to be *204 sterilized because they view the women's family sizes as excessive and believe that they are incapable of using contraceptives. [FN]83 Furthermore, the federal government still subsidizes sterilizations for women eligible for Medicaid coverage, though it will not pay for abortions. [FN]84 Thus, African Americans' distrust of family planning is justified.

D. Participation in Justifying Racism

Louis Agassiz, Samuel George Morton, Samuel Cartwright, and Josiah Clark were the leading U.S. academic physicians to advocate the theory that Blacks were biologically inferior to Whites. [FN]85 In fact, many physicians used their science to create elaborate theoretical systems to justify the difference in the medical treatment of Blacks and Whites. [FN]86 They advocated for the establishment of uniquely Southern-oriented medical education to address the unique diseases of Black slaves, such as drapetomania--the disease causing negroes to run away. [FN]87 Furthermore, it is important to illustrate that these men did not represent the lunatic

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fringe. Their ideas were widely held and accepted. For instance, Oliver Wendell Holmes, Dean of Harvard's Medical School from 1847 to 1853, believed in and promoted the scientific value of the work of these "scientists." In fact, Holmes held such regard for Samuel Morton's work that he considered Morton's research "permanent data for all future students of Ethnology" [FN}88

III. African American Distrust and Current Bioethical Issues

Just like the rest of America, the African American community is facing a number of bioethical issues including: abortion, disparate health status, racial barriers to access to health care, racial disparities in medical treatment, the Human Genome Project and genetic testing, organ transplantation, AIDS, physician assisted suicide and right to die, reproductive technology, and violence. Unlike the dominant American group, African Americans view these issues through an additional screen of fear and distrust. It is this fear and distrust that causes us to believe that the principles of bioethics: autonomy, beneficence, nonmaleficence, and justice, won't protect our community from mistreatment and abuse.

*205 A. Abortion

Abortion is an issue that deeply divides American society. Generally, the arguments center on right-to-life and pro-choice ideologies. The situation for African Americans is not that simple. On the one hand, abortion-rights activity has increased among African Americans. In fact, Black women choose abortion at twice the rate of their White peers (21 per 1,000 for Whites, 57 per 1,000 for Blacks). [FN}89 On the other hand, the debate over abortion is too narrow, failing to address issues of prenatal care, infant-mortality rates, or teen-pregnancy rates. [FN}90 Furthermore, while many African Americans believe that every woman has the right to decide about abortion, those same African Americans believe that abortion is genocide. [FN}91 Some African Americans believe that this increase represents a form of eugenics: "Black women do not realize that the people forcing abortion on our people as a panacea to our social problems have a long history of beliefs in eugenics. They have a long history of racism." [FN}92 In short, many African Americans view abortion as "elitist, *206 racist and genocidal." [FN}93 Thus, a bioethical discussion centered on either right-to-life or pro-choice principles fails to take into consideration the social problems driving African Americans to abortions or the fear that abortion is merely another form of genocide.

B. Disparate Health Status

To African Americans, the continued disparity between the health status of African Americans and European Americans is significant evidence that the health care system is not to be trusted.

Wounded, [racism] retreated to more subtle expressions from its most deeply entrenched bunker .

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.. [F]orms of sophisticated racism attached to economic opportunities unfortunately can still be found today. . . . [N]owhere is that better exemplified than in the rate of excess death among black Americans. [FN}94

“Excess death” represents the number of deaths actually observed prior to the age of seventy years, minus the number of deaths that would be predicted when age- and sex- specific death rates of the U.S. European American population are applied to the African American population. [FN}95

Compared to European Americans' mortality rate, African Americans experience 60,000 excess deaths a year. [FN}96 In particular, African American women have 53.12% excess deaths, as compared to European American women. [FN}97 African American women have excess deaths in every category but suicide. “African-American women had 324.1% more deaths due to homicides,” [FN}98 *126 “163% more deaths due to diabetes, 77.6% more deaths due to cerebrovascular disorders, 78.4% more deaths due to cirrhosis of the liver, and 78.4% more deaths due to heart disease than European-American women.” [FN}99 “African American women have a 178.43% excess maternal rate.” [FN}100

African American men have 52.67% excess death rate over European American men. [FN}101 African American men had 598.7% more deaths due to homicides; [FN}102 100% more deaths due to diabetes; 92.6% more deaths due to cerebral vascular disorders; 88.4% more deaths from cirrhosis of the liver; and 81.8% more deaths due to pulmonary infectious disease than European American men. [FN}103

Children are not immune. For instance, African American infants are *208 222.81% more likely to suffer from low birth weight and its accompanying handicaps. [FN}104 108.14% more African American infants die than do European American infants. [FN}105 “When compared to the infant mortality of other nations, African-Americans rank thirty-second among countries compared to European-Americans' twelfth-place ranking.” [FN}106

“The picture that is clearly painted by these health measurements is one of significant disparity between two races.” [FN}107 Few health problems are more pressing than the persistent excess of morbidity and early mortality among African Americans. [FN}108 In fact, if we were to consider Blacks and Whites in the United States to be different nations, White America ranked twelfth in age-adjusted mortality rates (near Italy and Australia), whereas Black America ranked thirty-third (near Romania and Czechoslovakia) in 1991. [FN}109

Without decent health, it becomes nearly impossible for African Americans to gain the other attributes--money, education, contacts, industry knowledge-- necessary to gain access to the American economic system. Despite technological advances, African Americans continue to be sicker than European Americans. Given this level of disparity, “trusting the health care system

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ain't always easy.”

C. Racial Barriers to Access

Racial barriers to access are a significant problem for African Americans. [FN]110 These barriers to access have their foundation in the historical *209 relationship between African Americans and Southern medical institutions. As slaves, African Americans were perceived as property. [FN]111 While some slave owners attempted to protect their own economic interests by providing minimal health care, most left the slaves to live or die as fate might befall them. [FN]112 After the Civil War, the Bureau of Refugees, Freedmen and Abandoned Lands (“Freedmen's Bureau”) was instituted to “furnish supplies and medical services” to the former slaves. [FN]113 However, the Freedman Bureau had very limited effect in providing services to former slaves. In fact, the Compromise of 1877 effectively ended the period of radical reconstruction which had been an attempt by the nation to make affirmative efforts in helping African Americans. [FN]114 During the Post-Reconstruction era, African Americans were excluded from health care by either prohibition or discrimination: “ Even where segregation and discrimination were not required by law they became *210 deeply ingrained in the mores. Such behavior became part of the American Way of Life. . . .” [FN]115 This “way of life” remained visible until the Civil Rights Movement of the 1960s. [FN]116 After the 1960s, health care institutions either fled predominantly African American communities or instituted policies which resulted in limited access to health care for African Americans.

The continuing racial barriers to access are evidenced in discrimination that occurs in hospitals, the availability of facilities in the community, the segregation of facilities, and the limited availability of medical providers. For instance, many hospitals discriminate by using patient referral and acceptance practice standards that limit access. [FN]117 Moreover, increasingly, hospitals that *211 serve the African American community are either closing, relocating, or becoming private. [FN]118 This is a particular problem since many of the traditional sources of health care in the African American community also are vanishing. At one point there were more than two hundred African American hospitals in the United States. African Americans relied on these institutions to “heal--and save--their lives.” [FN]119 By 1991, only twelve hospitals continued “struggling daily just to keep their doors open.” [FN]120

Other evidence of racial barriers limiting access to health care is manifested in the problem of patient dumping. [FN]121 An African American seeking care at a private hospital faces the possibility of being “dumped”; that is, the hospital may transfer an “undesirable” patient to a different facility. [FN]122 Congress passed the Emergency Medical Treatment and Active Labor Act (EMTALA) to prevent patient dumping. [FN]123 However, lack of enforcement of these legislative enactments makes patient dumping an ongoing problem. [FN]124 Further, hospitals are continuing efforts to find ways of bypassing the requirements of EMTALA. For instance, by rerouting patients before they arrive at the hospital, a hospital can avoid EMTALA's

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requirements. [FN] 125 *212 Consequently, patient dumping continues to be an issue that plagues African Americans.

Other evidence of various racial barriers to access is the segregation that exists in facilities. For instance, nursing homes are the most segregated publicly licensed health care facilities in the United States. Racial discrimination, some commentators assert, is the major factor explaining that type of segregation. While African Americans constitute only twelve percent of the nation's total population, the African American poverty rate (31%) is three times greater than the European American poverty rate (10%). [FN] 126 However, African Americans constitute only twenty-nine percent of the Medicaid population and twenty-three percent of the elderly poor. [FN] 127 More significantly, Medicaid expenditures for African Americans are only eighteen percent of total expenditures. [FN] 128 Only ten percent of Medicaid intermediate-care patients are African Americans.

The data on the actual numbers of White physicians who have offices in the African American community is not available. There are probably very few. Consequently, African American physicians have been an important aspect of filling the availability gap. Furthermore, despite being twelve percent of the population, African Americans are seriously underrepresented in health care professions. [FN] 129 Only three percent of physicians in the United States are *213 African Americans; [FN] 130 only two-and-one-half percent of dentists in the United States are African Americans; [FN] 131 and only a little over three-and-one-half percent of pharmacists are African Americans. [FN] 132

Racial barriers to access can take two forms. Barriers can be based on racist conduct that is intentional, or they can be based on conduct which, although not intentional, nevertheless results in a disproportionate disparate impact on African Americans. Much of the institutional racism historically has moved from intentional conduct to unintentional. While this classification may offer a distinction when assigning fault or culpability, the classification makes little difference to the African American feeling the adverse affects of discrimination. This legacy of a racist health care system persists today in African Americans who are sicker than European Americans and who continue to experience racial barriers to access. These continuing racial barriers reinforce African Americans' distrust of the health care system.

D. Racial Disparities in Medical Treatment

Perhaps the most troubling aspect of institutional racism in the health care system is the occurrence of racial disparities in the types of services ordered by physicians and in the provision of the medical treatment itself. [FN] 133 These disparities are well-documented. Despite higher rates of heart disease in *214 African Americans, European Americans are one-third more likely to undergo coronary angiography [FN] 134 and two to three times more likely to undergo bypass surgery. [FN] 135 Doctors advise African American women to gain less weight than White

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women during pregnancy. This outdated advice ignores the fact that sufficient weight gain is particularly important for Black women, who are twice as likely as White women to deliver low-birthweight babies. [FN]136 Doctors are more likely to dismiss the use of cardiopulmonary resuscitation (CPR) as a treatment option for African Americans, Asians, and Hispanics, than for Whites. [FN]137 European Americans are five to fifteen percent more likely to receive aggressive treatment. [FN]138 In fact, the most favored patient for long-term hemodialysis is a European American male between the ages of twenty-five to forty-four. [FN]139 A European American on dialysis is two-thirds more likely to receive a kidney transplant than a non-European American. [FN]140 Middle-income African Americans are less likely to receive a kidney transplant than middle-income European Americans. Elderly Blacks have greater difficulty obtaining care than elderly Whites, even though both groups are covered by the federal Medicare program. Hospitalization and death rates are *215 higher among elderly African Americans than elderly Whites. [FN]141 Of Medicare hospitalizations, African Americans are more likely to receive substandard care than other elderly patients and are more likely to be discharged while still unstable. [FN]142 When hospitalized with pneumonia, African Americans were less likely than European Americans to receive intensive care. [FN]143 This disparity in medical treatment persists even after controlling for clinical characteristics and income. [FN]144 African Americans with HIV are less likely than whites to receive drug therapies used to prevent pneumonia, a major killer of HIV-infected people. The problem exists without respect to income, education, or health insurance status. [FN]145

African Americans receive health care treatment different from the “preferred” patient, the European American male. Whether this difference is based on individual prejudices or medical school training, it is evidence of institutional racism that cannot be tolerated. Any patient seeking care from a physician should be able to be assured of the most appropriate medical treatment available. Irrespective of race, each patient should be assured that the physician will act in the patient's best interest. Every person should be assured that the physician will not let personal prejudice or medical prejudice influence the medical treatment. Under the current situation, an African American does not have those assurances. Is there any wonder that African Americans do not trust the health care system?

E. Human Genome Project and Genetic Testing

The Human Genome Project is a group of research projects, organized under the supervision of the federal government, devoted to the long-term goal of identifying all the genes of the human body. [FN]146 There are both positive *216 and negative ramifications of the Human Genome Project. [FN]147 The positive ramifications can be grouped into those which promote general scientific interest, [FN]148 and those that advance the diagnosis of disease [FN]149 and advance disease treatment. [FN]150 The negative ramifications include the potential for providing a basis for a eugenics program, [FN]151 problems with invasion of privacy, [FN]152 and problems with genetic testing. [FN]153 It is generally agreed that the potential for

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discrimination is significant and serious. The discriminatory use of genetic information is particularly relevant in the context of schools, [FN]154 employers and employees, [FN]155 and insurers. [FN]156 But what few acknowledge is that African Americans will be disproportionately affected by any genetic discrimination. [FN]157

There are three primary issues facing African Americans. Historically, European Americans have used genetic information to reinforce negative stereotypes about African Americans. [FN]158 Second, given the racial barriers to access and the racial disparity in medical treatment, the potential benefits of *217 gene mapping will be also be racially distributed. [FN]159 Third, given the disparate health status of African Americans, the money being used to support gene mapping should be used to address the social conditions which contribute to current health status problems. [FN]160 Developing a technology such as the Human Genome Project in a racist society would be like developing a bomb and giving it to a child. The United States has had a long history of using genetics in attempts to subjugate African Americans. [FN]161 Yet, as usual, the fears of African Americans are, at best, put on the back burner and are, at worst, discounted as unreasonable. [FN]162

F. Managed Care

Insurers, both private and government, are electing to ration health *218 insurance products that “manage” the patient's care. They do it through managed care products such as health maintenance organizations (“HMOs”), preferred provider organizations (“PPOs”), and individual practice associations (“IPAs”). As currently operated, these managed care products may cause more harm than good to African Americans. It is important to remember that managed care products have not developed in response to the poor health status or the lack of access to health care of African Americans, but rather to third-party payors' and employers' desire to control expenditures. The primary mechanisms that managed care products use to reduce expenditures are strict utilization review and financial risk-shifting. These mechanisms may operate in direct conflict to the goals of improving the health status of African Americans.

Strict utilization review requires the prospective denial or modification of health care services. Financial risk-shifting is the mechanism which ensures that doctors and providers will act as gatekeepers to health care services. It is assumed that the gatekeeper will continue to order necessary care and that only “unnecessary” care will be cut. Unfortunately, the definition of “unnecessary” services will, at best, be based on some statistical norm of the general population. At worst, it will be based on standards that are a result of studies on a middle-class, European American, fairly healthy, male population.

Regardless, managed care products will ultimately change the perceptions and expectations of society, physicians, patients, and third-party payors regarding what is owed to whom, what treatments are appropriate in what circumstances, and even what qualifies as a disease. [FN]163

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These altered perceptions may be contrary to the needs of African Americans and, without safeguards, could work to worsen the existing disparity in health status between European Americans and African Americans.

Quality assurance, utilization review, and practice parameters are essentially designed around data based on middle-class populations who generally have had “good,” if not excellent, access to health care services. [FN]164 African Americans have definitely not had excellent access to health care services. [FN]165 That lack of access coupled with other issues affecting *219 African Americans--racism, TE, 15 St. Louis U. Pub. L. Rev. 219>>--racism, homelessness, violence, drugs, etc.--means that they will come into managed care products with poorer health status and needing more, not less, health care services. [FN]166 In a system focused on decreasing utilization, it seems difficult to imagine that African Americans will receive “more” health care services, while others receive “less.” If managed care products do not provide culturally relevant care, then African Americans may have technical access to health care, but not quality health care.

Beyond these problems with utilization review and financial risk shifting, managed care products' continued focus on cost containment may be inherently antithetical to the needs of African Americans. Just as insurance had a “perverse influence” on health service delivery, [FN]167 so shall managed care products. Since third-party payors will make more when they treat less and spend less on hospitals and providers (infrastructure), [FN]168 they will, over time, tend to place increasingly stringent requirements on providers; they will fail to develop more expensive, but culturally appropriate treatment modalities; and they will refuse or minimize the expenditures necessary to develop adequate infrastructure for African Americans. [FN]169 If health providers and health organizations that serve the underserved population do not insist that the provision of culturally competent care be a basic component of any managed health care product, African Americans will not benefit as much as we hope from this so-called “health care reform.” [FN]170 Yet, these concerns are often ignored or minimized by most bioethicists. [FN]171 It will not be easy to trust managed care organizations to operate in any way but a discriminatory way.

G. Organ Transplantation

African Americans have disparate access to organ transplantation. African Americans wait almost twice as long as European Americans for their first transplant--13.9 and 7.6 months, respectively. [FN]172 Although European Americans represent only sixty-one percent of the dialysis population, they *220 receive seventy-four percent of all kidney transplants. [FN]173 In 1988, African Americans represented 33.5% of dialysis patients, but only 22.3% of kidney transplants went to Black patients. [FN]174 In fact, in any given year, European American dialysis patients have approximately a seventy-eight percent higher chance of receiving a transplant than African American dialysis patients. [FN]175 Most bioethicists attribute this

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disparity to African Americans' failure to donate organs. For instance, in 1988, Blacks donated only twelve percent of living-related transplants and only eight percent of cadaveric kidneys. [FN}176 However, this disparity also exists because of the level of mandated antigen matching required, a level that may be unnecessary for successful transplantation. [FN}177

Organ transplantation presents two conflicting problems for African Americans. African Americans do not have equitable access to available organ transplants as do European Americans. They are on waiting lists almost twice as long as European Americans, even when such factors as blood type, age, immunological status, location, and the decreased organ donations by African Americans are taken into account. [FN}178 In part, this is due to allocation rules such as “antigen matching rules which favor European Americans.” [FN}179 However, there are alternative allocation rules that could reduce, if not eliminate, the racial disparity in access to donated kidneys. [FN}180

The most common reasons for donor reluctance include: lack of information; religion; distrust of medical professionals; fear of premature death; a preference to donate only to members of the same race; and the failure of health care professionals to ask African American families for consent in an effective way. [FN}181 The fear of premature death is fueled by popular shows and *221 community rumors: In a fairly recent Law and Order telecast, a rich White man bought his daughter a perfect kidney from the surgeon. The surgeon obtained the organ by taking a medical team to a park and mugging a preselected victim. The victim was an African American man. [FN}182 Moreover, a popular story in the African American community is of a Hispanic man who was found “mugged” on the streets. When the ambulance took him to the hospital, he was declared brain dead and his organs were removed before his family was notified.

Thus, popular folklore fuels the fear of African Americans. In fact, it is not an unreasonable fear. The world's most enduring line of human cell cultures-- used to test the polio vaccine, new drugs, and potential cancer cures--was taken without informed consent from a Black woman in Baltimore who was treated for cervical cancer at Johns Hopkins Hospital in 1951. The cancer killed Henrietta Lacks, but the HeLa cells grown from her flesh live on in labs throughout the world. [FN}183 Laws in Pennsylvania, California, Florida, Michigan, Ohio, and Texas allow the coroner's office to remove eyes and brains from the bodies of the dead without prior consent or permission from next of kin. [FN}184 More often than not, African Americans are most affected by this law. [FN}185 Given the current level of mistreatment based on race, there is no reason why African Americans should believe that their bodies will not become a source of organs for European Americans. [FN}186

*222 H. Reproductive Technology

African American women like most women seek “reproductive choice.” [FN}187 They want the power to make genuine choices about their reproductive health. [FN}188 However, we tend

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not to have that choice because choice involves more than a “right to an abortion”; it involves the real ability to exercise the choice to have healthy children or not to have children at all. To have real reproductive choice, African American women, at a minimum, would need access to reproductive health care, including prenatal care; access to infertility services; freedom from coerced or ill-informed consent to sterilization; economic security, which could prevent possible exploitation of the poor with surrogacy contracts; freedom from toxins in the workplace; healthy nutrition and living space; and the right to safe, legal, and affordable abortion services. [FN]189

1. Reproductive Health--Workplace Toxins

African American women are less healthy than European American women, due in part to our overrepresentation in jobs that have high levels of workplace toxins. [FN]190 How to protect the reproductive health of women is a significant legal issue that will disproportionately affect African American women. The *223 leading case on the issue, *United Automobile Workers v. Johnson Controls, Inc.*, does little to help. [FN]191 Certainly, the decision protects women from forced sterilization in order to maintain higher paying jobs. However, because the decision does not address the work conditions which threaten the health and safety of women and their fetuses, African American women could be rendered infertile simply by doing their jobs. [FN]192 Reproductive health of African American women will continue to lag behind European American women as long employers are allowed to evade their responsibility for maintaining toxic-free environments. [FN]193

2. Reproductive Health Care

The lack of adequate prenatal care has resulted in both high maternal and infant mortality rates. In 1986, African American women were 3.8 times more likely than White women to die from pregnancy-related causes. [FN]194 Nearly one African American baby out of ten is born to a mother who received late or no prenatal care. Among African American teenage mothers under age fifteen, the proportion increases to two in ten. [FN]195

3. Contraception--Norplant

On December 10, 1990, the United States Food and Drug Administration (FDA) approved for general use in the United States the contraceptive Norplant, a long-acting drug. [FN]196 The potential abuse of Norplant is enormous and already apparent. On December 12, 1990, the *Philadelphia Inquirer* published an editorial entitled *Poverty and Norplant: Can Contraception Reduce The Underclass?* [FN]197 All fifty states have already incorporated *224 Norplant into their welfare systems, providing either reimbursement for the cost of Norplant to women on Aid to Families With Dependent Children or a cash bonus for those women who agreed to be implanted with the device. [FN]198 A number of high schools considered offering Norplant to teenage girls in order to prevent teenage pregnancy. [FN]199 The courts and legislatures have

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considered conditioning probation on the acceptance of Norplant. [FN]200 These Norplant proposals aimed at poor, African American women are based upon the concept that poor, Black women are “deviant” and thus less deserving of motherhood than White women. [FN]201

“Real” women were expected to be pious, pure, submissive, and domestic, middle-class and white. Black women, on the other hand, were presumed to conform to an entirely different set of characteristics-- characteristics which precluded them from ever being seen as ideal women. Generally, four controlling images of African-American women have emerged, all of which deviate from the middle- and upper-class standard of womanhood: (1) “mammy,” the faithful, obedient, nurturing, and caring domestic servant; (2) the “matriarch,” who is overly aggressive, unfeminine, and emasculating; (3) the “welfare mother,” who is irresponsible, lazy, and immoral; and (4) the “Jezebel,” who is sexually aggressive. . . . As a result, African-American women are seen as “somehow less female, perhaps even less human as well.” Thus, they are not maternal nor are they deserving of motherhood. [FN]202

*225 4. Sterilization

As discussed supra, African American women have not had genuine access to voluntary sterilization, but have been victims of involuntary surgical procedures that strip them of their ability to reproduce. After the abuses of the 1970s, the Department of Health and Human Services adopted regulations to ensure that informed consent was obtained for all federally funded sterilizations. [FN]203 However, there is inadequate monitoring of the consent regulations, and whatever data is collected is not published or made publicly available. [FN]204

5. Infertility Treatment

The ability to have children is as important as the ability to prevent having children. Yet, discussions of reproductive issues concerning African American women seldom include the need for infertility services. [FN]205 This is a significant issue because the risk of infertility is one and a half times greater for African Americans than for Whites. [FN]206 Yet, seventy-five percent of low-income women in need of infertility services have not received any services. [FN]207 “Given that the average fee for each infertility treatment is between \$2,055 and \$10,000, it is no wonder that poorer couples, a disproportionate number of whom are African Americans, do not pursue infertility treatment.” [FN]208 While infertility services are covered under Medicaid and Title X, [FN]209 little information is available on the amount of public funds spent on infertility services. [FN]210

6. Surrogacy [FN]211

There are two types of surrogacy arrangements. In the first type of arrangement, a couple with the female partner unable to bear children uses the male partner's sperm to inseminate a fertile

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woman, who becomes the *226 “surrogate mother.” [FN]212 Because this is a costly arrangement, it is limited to affluent couples who are disproportionately White. While there is significant potential for abuse of poor women, it is not likely that they will be African American, because an egg obtained from an African American woman would produce an African American child. [FN]213 The second type of surrogacy arrangement involves the use of an egg from a female donor who is not the surrogate. The egg is fertilized, then transferred into the uterus of another woman. This woman, the “gestational mother,” has no genetic connection to the child. [FN]214

This type of arrangement is significantly more dangerous to poor, African American women. It literally turns women into uterus prostitutes, wombs for rent. It raises the issue of what constitutes motherhood: is it biology, genetics or something else? [FN]215 If African Americans--and other women-- become breeder women for the affluent, it will be “painfully reminiscent of slavery and the days of the breeder woman whose feelings for her child, whether born out of love or out of rape, were disregarded when men with power over her made decisions about the child.” [FN]216

***227 IV. Violence as a Public Health Issue**

A young Black male's risk of becoming a homicide victim in the United States is one in twenty-seven, compared with one in two-hundred-five for young White males. The risk of becoming a homicide victim for young Black females is four times higher than for young White females in the White community. It is clear that violence in the African American community is a public health issue. However, even as the words “public health” arise, I have the cloud of the failed federal Violence Initiative to combat.

The Violence Initiative was a proposed federal initiative to combat violence in the inner-city, supposedly by focusing a more efficient effort toward collective policy making. [FN]217 However, the Violence Initiative was based on two disturbing premises. The first was that much of violent behavior in the inner city may have biological or genetic origins. [FN]218 The second premise was that “factors of individual vulnerability and predisposition to violent behavior exist--factors that may be detected at an early age.” [FN]219 To the African American community, the initiative's intervention and problem-solving policy mandate were to focus on the children of the inner city. [FN]220

*228 [T]he advent of the federal Violence Initiative threatened the personhood and the voice of African-Americans, and more particularly of African-American children, by fostering biological and reductionist theories of genetic linkage between criminally-violent behavior and inner-city youth. Furthermore, it decontextualized and dehistoricized the idea of violence, and devalued the worth of the African-American child by reinforcing gender and stereotypical concepts of African-American women and men. [FN]221

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The federal Violence Initiative failed because it wanted to focus on the people as the cause of the problem. Yet, a public health approach is warranted if it were to take proactive strategies to counteract the powerful economic and political forces of our society that legitimize these levels of violence. If we want to reduce violence, we will have to deal with the system that produces violence. Unfortunately, more often than not, a public health approach focuses on the human development in our community.

A focus on human development will necessarily be flawed because any actions or behaviors of the black community will be viewed in the historical context in which the American experience with slavery served to legitimize the image of African Americans as unworthy of respect and bodily integrity, and undeserving of psychological well-being. [FN]222 Furthermore, the images of sex and subjugation in the national psyche further legitimized the attempts to link social conditions with genetic deficiencies. [FN]223

Thus, even though they are free from slavery, Black men and women are bound now by a caste of race and poverty. They are “welfare queens,” and members of the “underclass.” They have become mothers and fathers of sons who have been labeled an “endangered species,” and of daughters who are caught in a cycle of “teenage pregnancy.” Subsuming and denying the individuality of African-Americans, these images represent “inherent and permanent inequality . . . apart from any environmental influence.” The social value of African-American children has never been recognized, and now their economic value is recognized as marginal or as having ceased to exist. Black people bear children who, by their very existence, become the tools for their own destruction, the murderers of their own spirits. These children become individuals who are seen as obsolete. African-American men and women in the inner city give birth to disposable children. [FN]224

V. Implication of an African American Bioethical Perspective

Bioethics “addresses the ethical problems posed by modern medicine and *229 biotechnology.” [FN]225 Bioethics is not a single, distinct academic discipline, but is comprised of practitioners from medicine, philosophy, theology, law, nursing, medical history, medical anthropology, medical sociology, and related fields. [FN]226 While bioethics lacks a single, accepted methodology, [FN]227 it has traditionally focused on “mid-level ethical principles,” such as autonomy, beneficence, justice, and nonmaleficence. [FN]228

These principles are intended to be a regulative guideline, stating conditions of the “permissibility, obligatoriness, rightness, or aspirational quality of actions *230 falling within the scope of the principle[s].” [FN]229 However, there have been a number of challenges to the content of the principles. [FN]230

Eurocentric bioethics focuses on the individual, ignoring the interests of others who are

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intimately affected, such as the family and the community. [FN]231 This focus on the individual is based on a philosophy that regards the self, and only the self, as the end per se. [FN]232 However, the African American perspective views this reliance on ethical egoism to be misplaced. [FN]233 African Americans believe that “it takes a whole village” to raise a child, and thus, at a minimum, African Americans view ethical egoism to be contradictory to the raising of healthy children. [FN]234 Furthermore, even as adults, none of us function as islands; we all must rely on others for, at a minimum, reaffirmation of our self-assessment. [FN]235

Second, Eurocentric bioethics embraces Kantian ethics, which are antithetical to Afrocentric bioethics. Kantian ethics require universal norms and an impartial perspective, which is inattentive to relationships and community. [FN]236 Kantianism privileges abstract reasoning over virtue, character, and moral emotions. [FN]237 Kantian ethics maintain that the only way we can morally constitute ourselves is by free and rational choice. [FN]238 It is the exclusivity of that claim that is troubling. African Americans believe that we morally constitute ourselves not only through free and rational choice but also through our parents and our community. [FN]239

Third, Eurocentric bioethics tends to view the patient or research subject generically, without attention to race, gender, or insurance status. [FN]240 As a result, the development of laws and bioethical principles, discourse, and *231 practices are informed by the values and beliefs of one group: White, middle-class, males. [FN]241

Eurocentric bioethical principles such as autonomy, beneficence, and informed consent do not have the same force when viewed through the African American bioethical perspective of distrust. These principles leave considerable room for individual judgment by health care practitioners. [FN]242 The flaw of a principle-based paradigm is that very judgment. The application of the principles will be subject to other values held by the society. In a racist society (such as ours), the judgment is often exercised in a racist manner.

Thus, Eurocentric bioethics has adopted rules and has applied them with little, if any, concern for how race or other characteristics affect the working of the rules. [FN]243 In fact, numerous studies have documented a disparity between traditional bioethical practice and the needs of minority populations. For instance, African Americans notably differ from European Americans, both in their unwillingness to complete advance directives and in the desires expressed regarding life-sustaining treatment. [FN]244 Substantially more African Americans and Hispanics “wanted their doctors to keep them alive regardless of how ill they were, while more . . . whites agreed to stop life-prolonging treatment under some circumstances. . . .” [FN]245

Eurocentric bioethics fail African Americans because bioethicists “believe, first, that people behave in ways that can so far be predicted a priori that empirical evidence about their behavior is superfluous and, second, that people *232 think and act rationalistically, seeking always to

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maximize and exercise autonomy.” [FN]246 Furthermore, when dealing with bioethical concepts, courts have shown little interest in dealing thoroughly with empirical evidence, or the effects of judicial doctrines. [FN]247 However, the reality is very different. [FN]248 People act in ways that are more consistent with the values they hold, rather than following any particular bioethical principles. [FN]249 And racism is a *233 strongly held value in our society.

African Americans have been experimented on without consent, thus violating the principle of autonomy. [FN]250 We have been treated and experimented on in ways which have caused us harm, thus violating the principles of nonmaleficence [FN]251 and beneficence. [FN]252 We have been given different treatment and provided different access to health care, thus violating the principle of justice. [FN]253 At best, the judgment in applying the articulated principles has been exercised fairly consistently in a manner which disadvantages and harms African Americans.

The implication for the African American community is the failure of bioethical problem-solving to take into consideration those factors important to solving problems in the African American community. Most of the problem-solving has been at odds with the affirmation of the African American individual and the African American community. In fact, for the most part, mainstream bioethicists have consistently neglected to comment on the social ills or injustices such as “the [African Americans'] enslavement, the injustices and discrimination they have suffered, the stereotyping of their language and culture, and their disadvantaged economic, political, educational, and health *234 status.” [FN]254 As a result of this lack of affirmation, or, this oppression, we are in danger of losing our own perspectives--our own gifts. [FN]255

The continued destruction of the African American community results from the lack of consideration given to our perspectives. The African American community has a history--and a present context--that is characterized by medical mistreatment and health care exploitation. European Americans have a history that is racist and “conspicuously indifferent to community, religion, virtue, and personal experience.” [FN]256 African Americans face the health care system with anxiety, fear, and disaffection. [FN]257 Such anxiety, fear, and distrust will not be alleviated until bioethics constructs a practical, ethical approach to the anxiety and fear which would lead to community empowerment. [FN]258 Such a practical approach would require behaviors such as: reinstatement of community hospitals; [FN]259 assuring urban perinatal health care; [FN]260 encouraging traditional lay-midwifery; [FN]261 and reestablishing the extended family. [FN]262 *235 However, such practical approach must be based on not only on the traditional Eurocentric principles but also on:

- recognizing the needs of the community and not just the individual self;
- formulating bioethical and legal solutions involving both the family and the community;

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- aggressively training health care providers and institutions about the African American perspective, thus making the barrier of distrust easier to overcome;
- eliminating the disparities in health status;
- aggressively reducing the existing disparities in health care delivery in the African American community.

One problem that some bioethicists may have with acknowledging an African American perspective is the failure of all African Americans to concur in a description of an ethical belief system. However, such a requirement is not necessary or even possible. Not all individuals of any group will believe or act alike. No one expects that all European Americans accept the dominant view in their culture. Nevertheless, a view may be an accurate description of some significant aspect of European American culture. However, my experience shows that attempts to assert, define, and explain the impact of bioethical or legal behavior on African American culture is met with resistance. European Americans often base the resistance on an assertion that such perceptions about African American culture are not representative. I often wonder if this resistance is based on some attempt--unconscious or conscious--to avoid having to truly structure a multi-cultural society and keep the Eurocentric view dominant. [FN}263 Until bioethicists begin to explicitly address these concerns, African Americans are not likely to begin to place their trust in the American health system. Ultimately, bioethicists must recognize the existence of a "spirit, a set of social structures and norms in African American life that are worthy of acquisition by Blacks and Whites." [FN}264

Footnotes

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My distrust of the health care system is typical of a belief held in the African American community: "I believe that the AIDS virus was developed in government labs for the purpose of controlling black folks." Annette Dula, African American Suspicion of the Healthcare System Is Justified: What Do We Do About It?, 3 Cambridge Q. Healthcare Ethics 347, 347 (1994) (citations omitted). "[M]any black Americans believe that AIDS and the health measures used against it are part of a conspiracy to wipe out the black race." The AIDS 'Plot' Against Blacks, N.Y. Times, May 12, 1992, at A22. "There's still so much fear and trepidation about what

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happened in Tuskegee, and it fuels the distrust blacks have of public health.” Cheryl Clark, *The Ghost of Tuskegee*, S.D. Union & Trib., Jan. 28, 1996, at D14. “Behind the facade of big hospitals, many African Americans can only see one big medical experiment.” Carol Stevens, *Research: Distrust Runs Deep; Medical Community Seeks Solutions*, Det. News, Dec. 10, 1995, at A12 (quoting Vernice Anthony, Senior Vice-President of the St. John Health System, who has seen the “paranoia”).

2

See generally Barbara A. Koenig & Jan Gates-Williams, *Understanding Cultural Difference in Caring for Dying Patients*, 163 W.J. Med. 244 (1995) (asserting that experiences of illness and death, as well as beliefs about the appropriate role of healers, are profoundly influenced by cultural background); Clark, *supra* note 1, at D14; Cynthia Hubert, *African Americans Breaking Silence on Reality of AIDS*, Sacramento Bee, Jan. 2, 1996, at A1 (reporting that the inherent distrust among African Americans of the public health system results in people not accessing the system); Carol Stevens, *Churches Preach the Gospel of Good Health*, Det. News, Dec. 11, 1995, at A1 (reporting that the lingering distrust of medical institutions has made it difficult for doctors to convince African Americans of the importance of screening tests); Stevens, *supra* note 1, at A12 (reporting concerns of African Americans about participating in medical research and screening tests); Sharon Voas, *Aging Blacks Sick, Scared Past Abuses, Tradition Keep Them From Clinic*, Pitt. Post-Gazette, Aug. 27, 1995, at B1 (reporting failure of aging African Americans to seek care because of fear of doctors, of the haunting memories of shoddy hospitals for “coloreds” they were relegated to as children, and of being used in medical experiments).

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Tom L. Beauchamp, *Response to Jorge Garcia*, in *African-American perspectives on Biomedical Ethics* 67, 72 (Harley E. Flack & Edmund D. Pellegrino eds., 1992) (maintaining that there is nothing particularly ethnic about the African American perspectives, since Native Americans may be as disposed to them as African Americans).

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Webster's II New College Dictionary 821 (1985).

5

Leonard Harris, *Autonomy Under Duress*, in *African-American Perspectives on Biomedical Ethics* 133, 134-35 (Harley E. Flack & Edmund D. Pellegrino eds., 1992) (discussing autonomy and health care as they relate to African Americans). See generally Cecil Helman, *Culture, Health and Illness* (1995) (defining medical anthropology and discussing its impact on health and

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disease issues); Charles Taylor, Multiculturalism And “The Politics Of Recognition” (1992); Marjorie Kagawa-Singer, Diverse Cultural Beliefs and Practices About Death and Dying in the Elderly, in Cultural Diversity and Geriatric Care: Challenges to the Health Professions (Darryl Wieland et al. eds., 1994) (recognizing that differences exist in the way cultures experience and express death and dying); Celia J. Orona et al., Cultural Aspects Of Nondisclosure, 3 Cambridge Q. Healthcare Ethics 338 (1994); P.V. Caralis et al., The Influence Of Ethnicity And Race on Attitudes Toward Advance Directives, Life-Prolonging Treatments, and Euthanasia, 4 J. Clin. Ethics 155 (1993); Nancy Adler et al., Socioeconomic Inequalities In Health: No Easy Solution, 269 JAMA 3140 (1993) (considering mechanisms through which socioeconomic status affects health); Judith Barker, Cultural Diversity-- Changing The Context Of Medical Practice, 157 W.J. Med. 248 (1992) (reporting on the need for more clinical information to assist in the medical care of indigenous, as well as immigrant groups in America); Margaret Lock, The Concept Of Race: An Ideological Construct, 30 Transcultural Psychiatric Res. Rev. 203 (1993) (arguing that the health and well-being of visible minorities will continue to suffer as long as decisions are based on race and ethnicity); Arthur Kleinman & Joan Kleinman, Suffering And Its Professional Transformation: Toward an Ethnography of Interpersonal Experience, 15 Cultural Med. & Psychiatric 275 (1991) (discussing the plight of Chinese society and its cultural experiences); Ladson Hinton IV & Arthur Kleinman, Cultural Issues and International Psychiatric Diagnosis, in International Review Of Psychiatry 111 (Jorge Alberto Costa e Silva & Carol Nadelson eds., 1993) (analyzing the differences between relativists and universalists and their views of a single psychiatric nosology); Arthur Kleinman, Patients and Healers in the Context of Culture (1980) (examining methods of healing throughout various cultures).

6

Edmund D. Pellegrino, Response to Leonard, Harris, in African-American Perspectives on Biomedical Ethics SSSSSSS 150, 151 (Harley E. Flack & Edmund D. Pellegrino eds., 1992); Harris, supra note 5, at 133-48 (telling stories, including the ‘Polar Tree Narrative,’ involving the application of biomedical principles in a way that disadvantaged African Americans).

7

Pellegrino, supra note 6, at 151.

8

Harris, supra note 5, at 133-35.

9

Annette Dula, Yes, There Are African-American Perspectives on Bioethics, in African-American

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Perspectives on Biomedical Ethics 193, 194 (Harley E. Flack & Edmund D. Pellegrino eds., 1992).

10

Marian Gray Secundy, Response to Kwasi Wiredu, in African-American Perspectives on Biomedical Ethics 99, 101 (Harley E. Flack & Edmund D. Pellegrino eds., 1992) (citing Mechal Sobel, *Trabelin' On: The Slave Journey to an Afro-Baptist Faith* 219 (1988)) (explaining that many West African world views used consensus to coalesce into African American culture).

11

Humanistic belief is one that focuses on the importance of the human being over all else. “[W]hat is good in general is what promotes human interests.” Kwasi Wiredu, *The Moral Foundations of African Culture*, in African-American Perspectives on Biomedical Ethics SSSSSSS 80, 81 (Harley E. Flack & Edmund D. Pellegrino eds., 1992); see also Secundy, *supra* note 10, at 103.

12

With a clear sense of individual responsibility comes an equally strong sense of the social reverberations of an individual's conduct. Thus, “[t]he primary responsibility for an action, positive or negative, rests with the doer, but a nontrivial, secondary responsibility extends to the individual's family and . . . to the . . . community.” Wiredu, *supra* note 11, at 83-84.

13

High value related to community belonging is based on a strong belief that all human beings deserve or ought to be helped. “Human beings . . . at all times, in one way or another, directly or indirectly, need the help of their [community].” *Id.* at 89; see also Secundy, *supra* note 10, at 103.

14

Secundy, *supra* note 10, at 102; see also Cheryl J. Sanders, *Problems and Limitations of an African-American Perspective in Biomedical Ethics: A Theological View*, in African-American Perspectives on Biomedical Ethics 165, 167-70 (Harley E. Flack & Edmund D. Pellegrino eds., 1992).

15

Most African Americans have parents, grandparents, or other ancestors who are not only of

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African descent, but also of European American, Asian American, Hispanic American, and Native American descent. My own family history is typical. On my maternal side, my grandmother's parents were Cherokee and African. My grandfather's parents were Italian and African. On my paternal side, my ancestors were all African.

16

Dula, supra note 1, at 347-57.

17

Id.

18

Id. at 347-50.

19

Michael Byrd & Linda C. Clayton, Race and Health Care, Black Health in the Jacksonian and Antebellum Periods, 1812-46: Growth, Change and Manifest Destiny (1996) (unpublished manuscript, on file with the Saint Louis University Public Law Review).

20

Id.

21

Dula, supra note 1, at 347-48; see also Todd L. Savitt, Medicine and Slavery: The Diseases And Health Care Of Blacks In Antebellum Virginia 282 (1978). "Slaves and the free poor of both races had little choice in the matter; the former had to abide by the master's decision, and the latter, by the physician's (since treatment was without charge)." Id. Access to medical facilities were often expanded to Blacks in order to have a constant flow of Blacks to be used as subjects for clinical instruction. Id. For example, in Virginia in 1853 through 1854, there was a proposal to establish the "Virginia Free Hospital" solely for Blacks. Id. at 285. Even though the proposal was never put into effect, "the state legislature deemed the [Medical College of Virginia's] need for clinical material sufficiently important enough to appropriate \$30,000 toward the construction of a new hospital in 1860." Id. at 286 (citation omitted).

22

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Dula, supra note 1, at 347-48.

23

Byard & Clayton, supra note 19, at 19.

24

Dula, supra note 1, at 348. Jefferson's efforts to sanction smallpox vaccination began in the spring of 1801 when he received some untested cowpox vaccine from Dr. Benjamin Waterhouse of Boston and forwarded a portion of it to a Washington physician. Savitt, supra note 21, at 294-95. Although the physician's results with the vaccine were unsuccessful, Jefferson nevertheless decided to conduct his own experiment by vaccinating two hundred slaves belonging to him, his son-in-law, and his neighbors. *Id.* at 295.

25

Byrd & Clayton, supra note 19, at 24.

26

Dula, supra note 1, at 348; see also Patricia A. Turner, *I Heard It Through the Grapevine: Rumor in African-American Culture* 67-70 (1993); Gladys-Marie Fry, *Night Riders in Black Folk History* YYYYYYYY 170-212 (1975); Savitt, supra note 21, at 293-301.

27

Savitt, supra note 21, at 299.

28

Dula, supra note 1, at 348.

29

Id.

30

Savitt, supra note 21, at 300.

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31

Id. at 298-99.

32

Id. at 301.

33

Byrd & Clayton, *supra* note 19, at 20; Diana E. Axelsen, Women as Victims of Medical Experimentation: J. Marion Sims' Surgery on Slave Women, 1845-1850, 2 Sage 10-13 (1985).

34

Byrd & Clayton, *supra* note 19, at 20-23.

35

Id. In fact, one slave, Anarcha, underwent twenty-nine major experimental surgeries over several years. Id.

36

Id. See generally George A. Bender, Great Moments in Medicine 236-44 (1966) (depicting the forerunners of gynecologic sciences); Albert S. Lyons, M.D. & R. Joseph Petrucelli, II, M.D., Medicine: An Illustrated History 523, 531 (1987); Deborah K. McGregor, Sexual Surgery and the Origins of Gynecology: J. Marion Sims, His Hospital, and His Patients (1989) (discussing Dr. Sims, his origins, and the birth of gynecology).

37

Dula, *supra* note 1, at 348-49; Stephen B. Thomas & Sandra Crouse Quinn, The Tuskegee Syphilis Study, 1932 to 1972: Implications for HIV Education and AIDS Risk Education Programs in the Black Community, 81 Am. J. Pub. Health 1499 (1991).

38

Dula, *supra* note 1, at 348-49.

39

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Id.

40

Id. at 348; Jean Heller, Syphilis Victims in U.S. Study Went Untreated for 40 Years, N.Y. Times, July 26, 1972, at A1.

41

On July 23, 1973, attorney Fred Gray filed a \$1.8 billion class action civil suit in the United States District Court of Alabama on behalf of all the Tuskegee Experiment participants. Thomas & Quinn, *supra* note 37, at 1502. In the complaint, the plaintiffs demanded \$3 million in damages for each living participant and a similar amount for the heirs of the deceased. James H. Jones, *Bad Blood: The Tuskegee Syphilis Experiment* 216 (1981). Among the defendants named in the complaint were the U.S. Government, U.S. Public Health Services, the Center for Disease Control, and the State of Alabama. Id. In December 1974, the U.S. Government agreed to pay a sum totaling \$10 million in an out-of-court settlement. Id. at 217. The plaintiffs agreed to cease further action for a cash payment of \$37,000 to each living syphilitic alive on July 23, 1973; \$15,000 to the heirs of the deceased; \$16,000 to every member of the living controls alive as of July 23, 1973; and \$5,000 to the heirs of deceased controls. Id. All participants and heirs had a three-year statute of limitations during which to file claims. Id. Unfortunately, in spite of attempted efforts by the Public Health Service to locate surviving participants and heirs, many of the four hundred syphilitic actives were never located. Id.

42

Harriet A. Washington, *Tuskegee Experiment Was But One Medical Study That Exploited African-Americans* [sic] *Infamous Research*, Balt. Sun, Mar. 19, 1995, at 1F.

43

Id.

44

Id.

45

Id.

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46

Id.

47

Id.

48

Id.

49

Id.

50

Id.

51

Deborah Larned, *The Epidemic in Unnecessary Hysterectomy*, in *Seizing Our Bodies: The Politics of Women's Health* 202 (Claudia Dreifus ed., 1977). See generally Andrea Asaro, *The Judicial Portrayal of the Physician in Abortion and Sterilization Decisions: The Use and Abuse of Medical Discretion*, 6 *Harv. Women's L.J.* 51, 93-101 (1983) (analyzing the relationship between the judiciary and physicians in abortion and sterilization cases); Dick Grosboll, *Sterilization Abuse: Current State of the Law and Remedies for Abuse*, 10 *Golden Gate Univ. L. Rev.* 1147, 1153-56 (1980) (discussing the historical perspective and current state-of-law involving low-income sterilization abuse).

52

Washington, *supra* note 42, at 1F.

53

Id.

54

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Id.

55

Dr. Stough was expelled several times from hospitals and prisons after men became sick and died from a variety of diseases stemming from his experiments. Id.

56

Id.

57

21 C.F.R. § 50.23(d) (1995).

58

Jones, *supra* note 41 (discussing discriminatory medical practices in the United States as “race medicine”). See generally Robert M. Veatch, Ethical Principles in Medical Experimentation, in *Ethical And Legal Issues Of Social Experimentation* 22-24 (Alice M. Rivlin et al. eds., 1974); Franz J. Ingelfinger et al., The Poor, in *National Academy of Science, Experiments And Research With Humans: Values In Conflict* 150 (1975).

59

Dula, *supra* note 1, at 349; Leslie Roberts, One Worked; The Other Didn't, 247 *Science* 18 (1990) (reporting that charges of racism were leveled at those who advocated that African Americans with sickle-cell anemia avoid having children).

60

Dula, *supra* note 1, at 349; see also Todd L. Savitt & Morton F. Goldberg, Herrick's 1910 Case Report of Sickle Cell Anemia: The Rest of the Story, 261 *JAMA* 266, 266-71 (1989); Robert B. Scott, Health Care Priority and Sickle Cell Anemia, 214 *JAMA* 731, 731-34 (1970).

61

Dula, *supra* note 1, at 349.

62

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Id.

63

Id.

64

Id.; see also Phillip Reilly, Genetics, Law, And Social Policy 67-68, 77-78 (1977) (highlighting the danger of legislative misunderstanding of genetics); Charles F. Whitten, M.D., Sickle-Cell Programming--An Imperiled Promise, 288 New Eng. J. Med. 318, 318-19 (1973) (discussing the negative aspects of the implementation of the sickle-cell testing program); Ira M. Rutkow & Jeffrey M. Lipton, Some Negative Aspects of State Health Departments' Policies Related to Screening for Sickle Cell Anemia, 64 Am. J. Pub. Health 217, 217-21 (1974) (analyzing the results of a survey mailed to all state Departments of Health).

65

Dula, supra note 1, at 349; see also Rutkow & Lipton, supra note 64, at 219.

66

Dula, supra note 1, at 349.

67

Id.; see also Lori B. Andrews, Confidentiality of Genetic Information in the Workplace, 17 Am. J.L. & Med. 75, 107-08 (1991) (discussing the employment discrimination in the 1970s faced by African Americans with the sickle-cell trait); Larry Gostin, Genetic Discrimination: The Use of Genetically Based Diagnostic and Prognostic Tests by Employers and Insurers, 17 Am. J.L. & Med. 109, 138-39 (1991) (discussing *Smith v. Olin Chem. Corp.*, 555 F.2d 1283 (5th Cir. 1977), in which an employer fired a worker with sickle-cell anemia because of concerns about the worker's health).

68

Dula, supra note 1, at 349; see also James E. Bowman, Genetic Screening Programs and Public Policy, 38 Phylon 117, 117-42 (1977) (discussing genetic screening programs, criticizing many of them as disguised scholarly research and labeling them as covers for racism). Genocide has been defined to include acts such as "imposing measures intended to prevent births within the group." Convention on the Prevention and Punishment of the Crime of Genocide, Dec. 9, 1948,

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art. II(d), 78 U.N.T.S. 277. According to the Convention, “group” includes a national, ethnic, racial, or religious group. *Id.* In 1986, the United States ratified the Genocide Convention. 132 Cong. Rec. S2327-50 (1986).

69

See Robert G. Weisbord, *Genocide? Birth Control and the Black American* (1975) (discussing the view held by some Blacks that family-planning programs are a potential means of race genocide); see also Kay Mills, *This Little Light of Mine: The Life of Fannie Lou Hamer* 274 (1993) (discussing Black activist Fannie Lou Hamer's view of abortion and birth control as a form of genocide); William A. Darity & Castellano B. Turner, *Family Planning, Race Consciousness and the Fear of Race Genocide*, 62 *Am. J. Pub. Health* 1454, 1454-56 (1972) (discussing the view held by some Blacks that family-planning programs are a potential means of race genocide).

70

Linda Gordon, *Woman's Body, Woman's Right: A Social History of Birth Control in America* 281-83, 332-33 (1976). By 1919, the influence of the eugenics campaign on the birth control movement headed by Margaret Sanger was clear. Sanger stated the following in an article published in the American Birth Control League's journal: “More children from the fit, less from the unfit--that is the chief issue of birth control.” *Id.* at 281.

71

Id. at 332-33 (citation omitted).

72

Dorothy E. Roberts, *Crime, Race and Reproduction*, 67 *Tul. L. Rev.* 1945, 1970-71 (1993) (citation omitted); see also Gordon, *supra* note 70, at 332 (stating that the “Negro Project” was intended to regulate the “mass of Negroes . . . particularly in the South, [who] still breed carelessly and disastrously, with the result that the increase among Negroes, even more than among whites, is from that portion of the population least intelligent and fit, and least able to rear children properly.”).

73

Charlotte Rutherford, *Reproductive Freedoms and African American Women*, 4 *Yale J.L. & Feminism* 255, 273 (1992). Sanger promoted the use of sterilization, abortion, and contraception to eliminate “human weeds.” See George Grant, *Grand Illusions: The Legacy of Planned*

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Parenthood 63, 65 (2d ed. 1992) (relating the Margaret Sanger story). In addition, other eugenicists were a significant part of the American Birth Control League. Gordon, *supra* note 70, at 82-83.

74

Dula, *supra* note 1, at 349-50.

75

Id. at 350.

76

Roberts, *supra* note 72, at 1971; see also *Walker v. Pierce*, 560 F.2d 609, 613 (4th Cir. 1977) (reversing judgment against a doctor who required Medicaid recipients to consent to undergo tubal ligation before he would deliver their third child), cert. denied, 434 U.S. 1075 (1978); Laurie Nsiah-Jefferson, *Reproductive Laws, Women of Color, and Low-Income Women*, 11 *Women's Rts. L. Rep.* 15, 30-31 (1989) (setting forth statistics demonstrating the disproportionate sterilization of minority women, particularly Black women).

77

Roberts, *supra* note 72, at 1971; see also *Cox v. Stanton*, 529 F.2d 47 (4th Cir. 1975) (reversing dismissal of a claim brought by a Black woman who was permanently sterilized after she agreed to temporary sterilization when threatened with termination of welfare benefits).

78

See *Relf v. Weinberger*, 372 F. Supp. 1196, 1199 (D.D.C. 1974), vacated, 565 F.2d 722 (D.C. Cir. 1977).

79

Dula, *supra* note 1, at 350.

80

Nsiah-Jefferson, *supra* note 76, at 31.

81

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Id.

82

Id.

83

Roberts, *supra* note 72, at 1971.

84

See, e.g., Rutherford, *supra* note 73, at 274. Compare 42 C.F.R. § 441.253 (1994) (authorizing federal funding for sterilizations) with 42 C.F.R. §§ 441.202-.203 (1994) (denying federal funding for abortions unless the life of the mother is endangered).

85

Byrd & Clayton, *supra* note 19, at 65-73.

86

Id.

87

Id.

88

Id.

89

Minority Update: Genocide to Some; Vital Choice to Others, American Political Network: Abortion Report, June 17, 1992, available in WESTLAW 06/17/92 APN-AB15.

90

See generally John D. Lantos, Race, Prenatal Care, and Infant Mortality, in "It Just Ain't Fair": The Ethics of Health Care for African Americans 67, 67-74 (Annette Dula & Sara Goering eds.,

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1994) (providing an overview of some factors affecting infant mortality, examining studies that support the position that the difference is genetic, and discussing the political implications of adhering to the genetic explanation of racial differences in infant mortality).

91

Fern Shen & Peter Pae, Calls for Peace Met With Caution, Wash. Post, Jan. 23, 1995, at D1 (reporting an anti-abortion demonstration where protester Barbara Bell maintained that abortion contributes to the genocide of African Americans); Leonard Hughes & Hamil R. Harris, End of Abortion Ban Draws Fire, Praise, Wash Post, Nov. 4, 1993, at J1 (reporting comments by Archbishop G. Augustus Stallings, head of the African American Catholic Congregation, acknowledging the right of women to choose, but insisting that abortion is genocide to African Americans); see also Mills, supra note 69, at 274 (discussing Black activist Fannie Lou Hamer's view of abortion and birth control as a form of genocide); Minority Update: Genocide to Some; Vital Choice to Others, supra note 89 (quoting SUN poll of Maryland residents: "more than 50 percent of blacks polled said they would support a law to keep most abortions legal . . . [while] [t]hirty-two percent of the black respondents said they would vote no."); Felicia R. Lee & Rachel B. Gold, Empty Womb, Essence, May 1990, at 51 (quoting Larry Hugick, Vice President of the Gallup Organization, Inc.: "The most conservative people on the abortion issue are Blacks, Hispanics and white Catholics."); Weisbord, supra note 69; Darity & Turner, supra note 69, at 1454-56 (discussing the view held by some Blacks that family-planning programs are a potential means of race genocide).

92

Women: Blacks "No Longer Silent" on Abortion, American Political Network: Abortion Report, Aug. 25, 1992, available in WESTLAW 08/25/92 APN-AB13 (quoting Akua Furlow of Black Americans for Life); see also Lee & Gold, supra note 91, at 51-53 (noting that author La Verne Powlis, who, ten years ago, sat on the board of Planned Parenthood of New York City, maintains that "any destruction of Black life is devastating for already embattled Black families.").

93

Minority Update: Genocide to Some; Vital Choice to Others, supra note 89 (quoting retired social worker, Erma Craven).

94

Vernellia R. Randall, Racist Health Care: Reforming an Unjust Health Care System to Meet the Needs of African-Americans, 3 Health Matrix 127, 141 (1993) (emphasis added) (citation omitted).

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[T]he theory of internal colonialism views blacks as slaves of society. The history of blacks in the US is traced, beginning with the introduction of slavery during the 1600s. The features of slavery--legal until the passage of the 13th Amendment in 1865--persisted as a form of semi-slavery [sic] 1960 and as a different form of institutionalized racism later.

Id. at n.64; see also Lonnie R. Bristow, M.D., *Mine Eyes Have Seen*, 261 JAMA 284, 284-85 (1989) (noting major health issues facing African Americans today). Since the civil rights and voting rights laws of the early 1960s, the United States has seen significant changes in the status of African-Americans. However, it is arguable whether “apartheid-U.S. . . . or whether economic segregation and the perpetuation of our essentially feudal status amount to its continuation, in fact, if not in law.” Ramona Hoage Edelin, *Toward An African-American Agenda: An Inward Look*, in *The State of Black America 1990* 173, 178 (Janet Dewart ed., 1990) (noting that death rate statistics seem to suggest that the feudal status of African Americans has continued in fact).

95

Randall, *supra* note 94, at 141; Bristow, *supra* note 94, at 284.

96

Randall, *supra* note 94, at 142.

97

Id. at 141.

98

Id. at 142. Health status includes not only physical health but mental health as well. Thus, in a racist, oppressive society, homicides are as much an indication of mental health and public health as are suicides. See generally Beth Alexander, *Violence: A Public Health Problem* (Editorial), 8 *Pediatrics for Parents* 8 (1992); Laurie Jones, *Gun Violence As Public Health Issue*, *Am. Med. News*, Nov. 16, 1992, at 3; C. Everett Koop, M.D. & George Lundberg, M.D., *Violence in America: A Public Health Emergency*, 267 JAMA 3075 (1992) (defining violence as a mental/public health issue, as well as a major social and political concern); Antonia C. Novello, M.D. et al., *A Medical Response to Violence*, 267 JAMA 3007 (1992) (referring to violence as an assault on the health of Americans); James S. Belloni et al., *Application of Principles of Community Intervention*, 106 *Pub. Health Rep.* 244, 244 (1991) (asserting that violence takes a high toll in “mortality, morbidity, quality of life, and use of health care resources. . .”). Moreover, violence has been a community problem from early American history. “Before there was professional law enforcement, everyone in a community was involved in crime prevention.”

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Id. Thus, recognizing homicide as a health issue is a return to deep-rooted ideas of community. Id. See generally Dan E. Beauchamp, Community: The Neglected Tradition of Public Health, Hastings Center Rep., Dec. 1985, at 28 (discussing the governmental power exerted to control or influence lifestyle choices of Americans).

99

Randall, supra note 94, at 142; Ronald M. Andersen et al., Black-White Differences in Health Status: Methods or Substance?, in Health Policies and Black Americans 84 (David P. Willis ed., 1989) (citing the National Center for Health Statistics 1986a, Table 21) (discussing the national health policies on the health status of the Black population in the United States).

100

Randall, supra note 94, at 142. “This is the rate of death per 100,000 live births from deliveries and complications of pregnancy, childbirth and the immediate period after childbirth (the puerperium).” Id. at n.70 (citing U.S. Dept. of Health & Human Services, Health Status of Minorities and Low Income Groups: Third Edition 20 (1991) (Table 1)).

101

Id. at 141 n.66 (citing U.S. Dept. of Health & Human Services, Health Status of Minorities and Low Income Groups: Third Edition 26-27, 143 (1991) (Table 13; Table 3)).

102

Id. at 142 (“The homicide rate for African-American males living within Standard Metropolitan Statistical Areas (SMSAs) is more than twice that for young African-American males residing outside SMSAs.”); id. at 142 n.71 (citing Belloni, supra note 98, at 245-46; Homicide Among Young Black Males-- United States, 1970-1982, 34 Morbidity & Mortality Wkly. Rev. 629-33 (1985)).

103

Id. at 142; Andersen, supra note 99, at 84 (quoting National Center for Health Statistics 1986a, Table 21).

104

Randall, supra note 94, at 140 (citing U.S. Dept. of Health Human Services, Health Status of Minorities and Low Income Groups: Third Edition 108 (1991) (Table 10)).

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105

Id. at 143.

106

Id.

107

Id.; see also H.R. Rep. No. 804, 101st Cong., 2d Sess. 19 (1990), reprinted in 1990 U.S.C.C.A.N. 2311, 2330 (finding that African Americans are disproportionately represented among individuals from disadvantaged backgrounds and that the health status of individuals from disadvantaged backgrounds, including racial and ethnic minorities, in the United States is significantly lower than the health status of the general population of the United States).

108

See Perils of Being Born Black: Life Expectancy for African Americans Is Sinking, *Time*, Dec. 10, 1990, at 78, available in 12/10/90 *Time Mag.* 78, 1990 WL 2757574 (asserting that the higher mortality rates of African Americans stem not only from those factors which relate directly to the perils of living in poor, violent neighborhoods, but that other socio-economic problems, including second-rate education and inadequate access to doctors and hospitals, also hold down African Americans' life expectancy rates).

109

Randall, *supra* note 94, at 143 n.75.

110

See generally Jean J. Schensul & Barbara H. Guest, Ethics, Ethnicity, and Health Care Reform, in "It Just Ain't Fair": The Ethics of Health Care for African Americans 24 (Annette Dula & Sara Goering eds., 1994) (advocating the creation of new, community-based and culturally appropriate health care options); Vernellia R. 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 (1994) (using President Clinton's 1993 Health Security Act proposal as a basis for analysis, the author analyzes the potential for health care reform for ethnic Americans and concludes that health care reform will fail ethnic Americans and the poor).

111

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Slavery in North America was one of the “harshes[t] form[s] of social relations ever to exist.” Alphonso Pinkney, *Black Americans* 2 (4th ed. 1993). The slave had no rights and received no protection from society. The slave owner had absolute power over the slave. *Id.*

112

Id. at 6; Woodrow Jones, Jr. & Mitchell F. Rice, *Black Health Care: An Overview*, in *Health Care Issues in Black America: Policies, Problems & Prospects* 6 (Woodrow Jones, Jr. & Mitchell F. Rice eds., 1987); see also Mitchell F. Rice, *On Assessing Black Health Status: A Historical Overview*, 9 *Urb. League Rev.* 6 (1985-1986). The dual status of slaves as valuable property and as persons with human rights may have encouraged some slave owners to provide at least minimal health care. See generally J. Thomas Wren, *A Two-Fold Character: The Slave as Person and Property in Virginia Court Cases, 1800-1860*, 24 *S. Stud.* 417-31 (1985) (maintaining that although slaves were perceived as property in the antebellum South, Virginia courts often recognized their humanity as well). By 1860, the Southern legal system had begun to accept an implicit duality in the states of the slaves as both property and person. See Arthur Howington, “A Property of Special and Peculiar Value”: The Tennessee Supreme Court and the Law of Manumission, 44 *Tenn. Hist. Q.* 302-17 (1985) (discussing a Tennessee court's recognition of limited humanity for slaves); Winstanley Briggs, *Slavery in French Colonial Illinois*, 18 *Chi. Hist.* 66, 75 (1989-1990) (arguing that the high cost of slaves and the risk of offending tribal neighbors led the settlers to treat their slaves as subordinate, but valuable property).

113

Pinkney, *supra* note 111, at 19 (citing John H. Franklin, *Reconstruction: After The Civil War* 36-37 (1961)).

114

Throughout the period of Reconstruction, attempts were made to obstruct the progress toward “racial democracy.” Pinkney, *supra* note 111, at 20. The 1876 election was in dispute between Rutherford B. Hayes (Republican) and Samuel Tilden (Democrat). Hayes was declared the winner with the understanding that the remaining troops in the South would be withdrawn, the South would be accorded home rule, and with the assurance that the “dominant whites [would have] political autonomy and nonintervention in matters of race and policy. . . .” *Id.* at 21 (citing C. Vann Woodward, *Reunion and Reaction: The Compromise of 1877 and the End of Reconstruction* 246 (1966)). Thus, the Republican Party “abandon[ed] the blacks to former slaveholders . . . [and the] compromise signaled a return toward slavery. . . .” *Id.*

115

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Jones & Rice, *supra* note 112, at 6. For instance, in 1875, Congress passed the Civil Rights Act which made it a crime for a person to deny any citizen equal access to accommodations in inns, public conveyances, theaters, and other places of amusement. Civil Rights Act of 1875, 18 Stat. 335 (1875). In 1883, the Supreme Court declared the Civil Rights Act of 1875 unconstitutional. *The Civil Rights Cases*, 109 U.S. 3 (1883). In 1896, the Court ruled that separate (segregated) facilities for African Americans and European Americans did not violate the Thirteenth or Fourteenth Amendment. Setting the pattern for race relations for more than three decades, the ruling declared that “[i]f one race be inferior to the other socially, the constitution of the United States cannot put them upon the same plane.” *Plessy v. Ferguson*, 163 U.S. 538, 552 (1896).

116

In 1954, the Court questioned the “separate but equal” doctrine of *Plessy v. Ferguson*. *Brown v. Board of Educ.*, 347 U.S. 483 (1954). In particular, in a unanimous decision, the Court found that legally sanctioned racial segregation is usually interpreted as connoting the inferiority of blacks, which adversely affects the educational development of black children. *Id.* at 494. “Any language in *Plessy v. Ferguson* contrary to this finding is rejected.” *Id.* at 494-95. *Brown v. Board of Education* was a significant milestone in civil rights. However, it was the Civil Rights Movement of the 1960s which culminated in the Civil Rights Act of 1964 and the Voting Rights Act of 1965, which resulted in many of the overt signs of discrimination being eliminated. In particular, the Civil Rights Act of 1964: prohibited the denial of the right to vote in national elections because of race and made a sixth grade education a presumption of literacy (Title I); prohibited discrimination in places of public accommodation (Title II); authorized the Justice Department to file suits to desegregate public facilities (Title III); authorized the Justice Department to file suit to desegregate public schools or colleges (Title IV); established the Commission on Civil Rights (Title V); prohibited discrimination in federally financed programs (Title VI); prohibited discrimination in employment (Title VII); authorized the gathering of registration and voting statistics based on race (Title VIII); allowed for federal appeals court intervention in civil rights cases to be remanded to state courts (Title IX); and established the Community Relations Service in the Department of Commerce (Title X). Civil Rights Act of 1964, Pub. L. No. 88-352, 78 Stat. 241-67 (codified as amended in scattered portions of Titles of the United States Code sections 28 and 42).

117

Randall, *supra* note 94, at 149.

These practices restrict the admission of African-Americans to hospitals. Discriminatory admission practices include:

- Layoffs of recently hired African-American physicians--where those African-American

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physicians admit most of the African-American patients served by the hospital;

- Not having physicians on staff who can accept Medicaid patients;
- Requiring pre-admission deposits as a condition of obtaining care;
- Refusing to participate in programs to finance care for low-income patients not eligible for Medicaid; and,
- Accepting only patients of physicians with staff privileges when the patients of such physicians do not reflect the racial composition of the local community.

Id. (citations omitted).

118

“In a study done between 1937-1977, researchers showed that the likelihood of a hospital's closing was directly related to the percentage of African-Americans in the population. Throughout the 1980s many hospitals relocated from heavily African-American communities to predominantly European-American suburban communities.” Id. at 149-50 (citations omitted).

119

The Crisis of the Disappearing Black Hospitals, *Ebony*, Mar. 1992, at 23.

120

Id.

121

“The transfer is medically appropriate only when the care required is not available at the transferring hospital. However, many transfers are for economic reasons, i.e., the patient was either uninsured or unable to make admission deposits. African-Americans are disproportionately affected by these practices.” Randall, *supra* note 94, at 151-52 (citations omitted).

122

See generally Geraldine Dallek & Judith Waxman, “Patient Dumping”: A Crisis in Emergency Medical Care for the Indigent, 19 *Clearinghouse Rev.* 1413 (1986) (describing the recent attempts by local, state, and federal governments to eliminate patient dumping).

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123

Randall, *supra* note 94, at 152.

124

“For instance, as of October 30, 1990, only 530 facilities had been investigated; only 139 facilities were found in violation of the statute; and only five facilities actually lost their Medicare contracts.” Randall, *supra* note 94, at 153 (citations omitted).

125

Randall, *supra* note 94, at 153-54.

In Johnson [*v. University of Chicago Hosps.*, 982 F.2d 230 (1992)], a parent called the paramedics after her baby went into cardiac arrest. The paramedics contacted University of Chicago hospital. The hospital told the paramedics to take the child to another hospital even though it was only five blocks away. The child was taken to a hospital without a pediatric intensive care unit and had to be transferred to another hospital. The child died after admission to the second hospital. The plaintiff sued on common law claims and for violation of COBRA. The district court dismissed and the Seventh Circuit upheld the dismissal of the COBRA claim. The Seventh Circuit noted that ‘In accordance with the plain meaning of the statutory language, we do not believe that the infant ever ‘came to’ the hospital or its emergency department. For purposes of COBRA, a hospital-operated telemetry system is distinct from that same hospital's emergency room.’ The court went on to acknowledge that a ‘. . . hospital could conceivably use a telemetry system to dump patients’; nevertheless, the court held that the ‘statute does not expressly address the question of liability in such a situation.’ Thus, the Seventh Circuit leaves the door open for other hospitals to continue dumping patients, most of whom will be African-Americans.

Id. (citations omitted).

126

Bureau Of The Census, U.S. Dept. of Commerce, Series P60-184, Current Population Reports, Consumer Income: Money And Poverty Status In The United States: 1992 xii (1993).

127

Racial Disparities in Medicaid Coverage for Nursing Home Care, An African American Health Care Agenda: Strategies for Reforming an Unjust System (NAACP Legal Defense & Educ.

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Fund, Inc., Baltimore, MD), Oct. 31, 1992.

128

Id.

129

See generally Warren J. Ferguson, The Physician's Responsibility to Medically Underserved Poor People, in "It Just Ain't Fair": The Ethics of Health Care for African Americans 122 (Annette Dula & Sara Goering eds., 1994) (arguing that physicians and their organizations must take responsibility for understanding attitudes and values that shape their delivery of health care to the underserved).

130

Jones & Rice, *supra* note 112, at 12 (citation omitted). Lack of African American representation in medicine is traceable to segregation in medical schools. *Id.* at 11. For instance, an African American did not receive a degree in an American school until 1847. While some White schools (nine) admitted African Americans prior to the Civil War, most schools did not. In fact, even in 1971, twenty-one medical schools out of eighty-five still had no African American students. *Id.* Even with the admission of African Americans to predominantly White schools, the African American medical schools, Howard University and Meharry Medical School, still train seventy-five percent of African American physicians. Donald E. Wilson, M.D., Minorities and the Medical Profession: A Historical Perspective and Analysis of Current and Future Trends, 78 J. Nat'l Med. Ass'n 177, 178 (1986). See generally Max Seham, M.D., Blacks And American Medical Care 20-21 (1973) (discussing the correlation between racism and infant mortality); U.S. Dept. Of Health & Human Services, Minorities & Women In The Health Fields 19 (1990) (Table 3).

131

Jones & Rice, *supra* note 112, at 12 (citation omitted); U.S. Dept. Of Health & Human Services, *supra* note 130, at 19 (Table 3); see also Amanda Husted, Shortage of Black Dentists Has Ill Effect in Community, Atlanta J. & Const., Aug. 19, 1991, at B3 (discussing effects of the shortage of African American dentists on the community).

132

Jones & Rice, *supra* note 112, at 12 (citation omitted); U.S. Dept. Of Health & Human Services, *supra* note 130, at 19 (Table 3).

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133

One wonders how much of the disparate treatment is a legacy in medical practice from slavery when “doctors frequently complained that they were unable to administer treatment because the slaves were not amenable to the same medical treatment as white patients.” Pinkney, *supra* note 111, at 5.

134

Council on Ethical and Judicial Affairs, *Black-White Disparities in Health Care*, 263 JAMA 2344 (1990); see also Mark B. Wenneker, M.D. & Arnold M. Epstein, M.D., *Racial Inequalities in the Use of Procedures for Patients with Ischemic Heart Disease in Massachusetts*, 261 JAMA 253 (1989).

135

Council on Ethical and Judicial Affairs, *supra* note 134, at 2344-45; see also Albert Oberman, M.D. & Gary Cutter, Ph.D., *Issues in the Natural History and Treatment of Coronary Heart Disease in Black Populations: Surgical Treatment*, 108 Am. Heart J. 688, 688-94 (1984) (discussing results of study showing a preferential selection of whites for coronary artery bypass grafting); cf. Charles Maynard et al., *Blacks in the Coronary Artery Surgery Study (CASS): Race and Clinical Decision Making*, 76 Am. J. Pub. Health 1446, 1446-48 (1986) (finding that rate of bypass surgery could not be explained by differences in clinical or angiographic characteristics).

136

Carol Stevens, *System, Race and Suspicion Promote Medical Disparities*, Det. News, Dec. 10, 1995, at A11. Because studies show a strong correlation between a mother's weight gain and her baby's birthweight, experts now advise pregnant women to gain a minimum of thirty pounds. *Id.* However, the study showed most African American women were being told by their physicians to gain less than twenty-two pounds. *Id.*

137

Id.

138

Council on Ethical and Judicial Affairs, *supra* note 134, at 2345; see Carl M. Kjellstrand & George M. Logan, *Racial, Sexual and Age Inequalities in Chronic Dialysis*, 45 Nephron 257, 260 (1987) (“[I]n 3 of 4 categories, blacks received less dialysis than whites.”).

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139

See Council on Ethical and Judicial Affairs, *supra* note 134, at 2345; Kjellstrand, *supra* note 138, at 260.

140

Id.; see also Carl M. Kjellstrand, Age, Sex, and Race Inequality in Renal Transplantation, 148 *Archives Internal Med.* 1305, 1307 (1988); Paul W. Eggers, Effect of Transplantation on the Medicare End-Stage Renal Disease Program, 318 *New Eng. J. Med.* 223, 229 (1988) (reporting that while African Americans accounted for thirty-three percent of patients with end-stage renal problems, they were only twenty-one of the patients who received kidney transplants).

141

Stevens, *supra* note 136, at A11.

142

Id.

143

Council on Ethical and Judicial Affairs, *supra* note 134, at 2345; see also John Yergan, M.D. et al., Relationship Between Patient Race and the Intensity of Hospital Services, 25 *Med. Care* 592, 600, 603 (1987) (suggesting that non-White pneumonic patients receive fewer services, especially with regard to intensive care).

144

Council on Ethical and Judicial Affairs, *supra* note 134, at 2345; Yergan, *supra* note 143.

145

Stevens, *supra* note 136, at A11.

146

See Jerry E. Bishop & Michael Waldholz, *Genome: The Story of the Most Astonishing Scientific Adventure of Our Time--The Attempt to Map All the Genes in the Human Body* (1990) (discussing the monumental task of mapping the human genes); Julia Walsh, *Reproductive*

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Rights and the Human Genome Project, 4 S. Cal. Rev. L. & Women's Stud. 145, 145-47 (1994). The "Human Genome Project" ("HGP") is a worldwide research endeavor with the goal of analyzing the structure of human DNA and determining the location of approximately 100,000 human genes. U.S. Dep't Of Health & Human Services, Understanding Our Genetic Inheritance: The U.S. Human Genome Project (1992). The Department of Energy decided that the project was necessary in order to begin to understand the thousands of genetic diseases that afflict humans. The National Institutes of Health has joined the project and is the major source of funds for all biomedical research in the United States. Darryl Macer, Whose Genome Project?, 5 Bioethics 183, 184, 188 (1991).

147

Walsh, supra note 146, at 147.

148

Id. at 147-48; see also Office of Technology Assessment, U.S. Cong., Pub. No. OTA-BA-373, Mapping Our Genes--The Genome Projects: How Big, How Fast? 24 (1988).

149

Walsh, supra note 146, at 147-48. The Office of Technology Assessment lists a number of diseases for which companies are presently developing (or already have developed) DNA probes for diagnosis. This list includes sickle cell anemia, cystic fibrosis, Duchenne muscular dystrophy, Hemophilia B, Huntington's disease, and Down's syndrome (phenylketonuria). Office of Technology Assessment, supra note 148, at 57.

150

Walsh, supra note 146, at 153.

151

Id. at 151-53; Sumner B. Twiss, Problems of Social Justice in Applied Human Genetics, in Genetic Counseling: Facts, Values, and Norms 255, 255-62 (Alexander M. Capron et al. eds., 1979). But see James E. Bowman, Genetic Screening: Toward a New Eugenics?, in "It Just Ain't Fair": The Ethics of Health Care for African Americans 165-181 (Annette Dula & Sara Goering eds., 1994) (defending the need for scientific inquiry even if abuses occur).

152

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Walsh, *supra* note 146, at 153-54.

153

Id. at 157-58; Twiss, *supra* note 151, at 257.

154

Dorothy Nelkin & Laurence Tancredi, *Dangerous Diagnostics: The Social Power of Biological Information* 106-32 (1994).

155

Gostin, *supra* note 67.

156

See, e.g., Kathy L. Hudson et al., *Genetic Discrimination and Health Insurance: An Urgent Need for Reform*, *Science*, Oct. 20, 1995, at 391; Gostin, *supra* note 67, at 117-19.

157

Patricia A. King, *The Past as Prologue: Race, Class, and Gene Discrimination*, in *Gene Mapping: Using Law and Ethics as Guides* 94 (George J. Annas & Sherman Elias eds., 1992) (discussing the potential for correlations between genetic susceptibility to disease and group membership used to discriminate against racial and ethnic minorities).

158

Id.

159

Id.

160

Id. In 1991, the United States contributed \$136 million to the HGP, with \$90 million coming from the National Institutes of Health and \$46 million coming from the Department of Energy. Although the total cost of the HGP is currently unknown, it is estimated that the United States, who has so far contributed 50% of the total cost of the project, will contribute more than \$3

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billion over the next 15 years. U.S. Dep't of Health & Human Services, Understanding Our Genetic Inheritance: The U.S. Human Genome Project, *supra* note 146.

161

See, e.g., Alfreda A. Sellers-Diamond, Disposable Children in Black Faces: The Violence Initiative as Inner-City Containment Policy, 62 UMKC L. Rev. 423, 459-60 (1994) (citing Samuel F. Yette, The Choice: The Issue Of Black Survival In America 82, 249 (1971)). For instance, Dr. Frank R. Ervin and Dr. Lawrence Razavi conducted a research project that suggested that normal individuals and criminals could be distinguished genetically, as indicated by their fingerprints. *Id.* It was hoped that the tests for this defect would “serve as a screening device for men upon entry into the military or perhaps at the time they first entered the criminal justice system.” *Id.* at 460. Although “the XYY theory for the association of abnormal fingerprints with an additional Y chromosome” was later discredited, there persists a popular belief in the theory. *Id.*

Furthermore, there persists a popular belief in the relationship between race and intelligence. This belief was fueled by Dr. Arthur R. Jensen's “discovery” of the so-called genetic relationship between race and I.Q. *Id.* at 460 (citing Arthur R. Jensen, How Much Can We Boost IQ and Scholastic Achievement?, 39 Harv. Educ. Rev. 1 (1969)). According to Jensen, “African-Americans averaged about fifteen points below the average of Whites on IQ tests [suggesting] that this phenomenon was responsible for a difference in scholastic aptitude between the groups.” *Id.*

162

The Office of Technology Assessment has acknowledged the potential problems raised by eugenics programs, stating:

The ethical debate about eugenic applications more properly focuses on how to use new information rather than on whether to discover it. Eugenic programs are offensive because they single out particular people and therefore can be socially coercive and threatening to the ideas that human beings have dignity and are free agents.

Office of Technology Assessment, *supra* note 148, at 84. Susan Rae Peterson notes that genetic testing and prenatal diagnosis tend to depersonalize women and childbirth. Susan Rae Peterson, The Politics of Prenatal Diagnosis: A Feminist Ethical Analysis, in *The Custom-Made Child? Women-Centered Perspectives* 95, 101-02 (Helen B. Holmes et al. eds., 1981).

163

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See Alexander M. Capron, Containing Health Care Costs: Ethical and Legal Implications of Changes in the Methods of Paying Physicians, 39 Case W. Res. L.R. 708 (1986) (concluding that the changes in access and delivery of health care in the United States must be justified ethically, as well as economically).

164

See generally Vernellia R. Randall, Ethnic Americans, Long-Term Health Care Providers, and the Patient Self-Determination Act, in Patient Self-Determination in Long-Term Care: Implementing the PSDA in Medical DecisionsSSSSSSS 126-27 (Marshall B. Kapp ed., 1994) (explaining how the Patient Self-Determination Act is a representation of one subculture alone: “European-American, middle-class, and middle-aged.”).

165

Id.

166

Id.

167

Capron, *supra* note 163.

168

W.G. Manning et al., A Controlled Trial on the Effect of a Prepaid Group Practice on Use of Services, 310 New Eng. J. Med. 1505-10 (1984).

169

See generally Randall, *supra* note 164.

170

Id.

171

Id.

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172

Office of Inspector General, *The Distribution of Organs for Transplantation: Expectations and Practices* 8 (1991). See generally Ian Ayres et al., *Unequal Racial Access to Kidney Transplantation*, 46 *Vand. L. Rev.* 805 (1993) (discussing the access and distribution frequency of kidney transplants among racial groups); Bertram L. Kasiske et al., *The Effect of Race on Access and Outcome in Transplantation*, 324 *New Eng. J. Med.* 302-308 (1991) (finding that African Americans have a four-fold higher risk for end-stage renal disease--irreversible kidney failure--as well as a higher prevalence).

173

Health Care Financing Administration, *End Stage Renal Disease Patient: Profile Tables* (1988); Ayres, *supra* note 172, at 808-10.

174

Ayres, *supra* note 172, at 810.

175

Id. at 808.

176

Id. at 809.

177

Office of Inspector General, *supra* note 172, at 11. Studies from New York, Los Angeles, Miami, and Washington D.C. document that Blacks were markedly underrepresented in donor statistics. Clive O. Callender, *Organ Donation in the Black Population: Where Do We Go From Here?*, 19 *Transplantation Proc.* 36 (1987); Luis M. Perez et al., *Organ Donation in Three Major American Cities With Large Latino and Black Populations*, 46 *Transplantation Proc.* 555 (1988) (noting that Black families were two to three times less likely to consent to organ donation than White families).

178

J. Michael Soucie et al., *Race and Sex Differences in the Identification of Candidates for Renal Transplantation*, 19 *Am. J. Kidney Disease* 414 (1992) (concluding that race and gender

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differences persisted after controlling for the health status and socioeconomic factors of the patients).

179

Ayres, *supra* note 172, at 809-10.

180

Id. at 809.

181

Id. (citing Clive O. Callender et al., Attitudes Among Blacks Toward Donating Kidneys for Transplantation: A Pilot Project, 74 Nat'l Med. Ass'n J. 807 (1982)); The Partnership for Organ Donation and The Annenberg Washington Program, Solving the Donor Shortage By Meeting Family Needs: A Communications Model 4 (Oct. 30-31, 1990) (suggesting that requests for consent may be more effective if they came from persons of the same race); Orly Hazony, Increasing the Supply of Cadaver Organs for Transplantation: Recognizing That the Real Problem is Psychological Not Legal, 3 Health Matrix 219 (1993) (discussing historical perspectives on organ shortages, the current failure to meet existing needs for donations, suggestions for increasing awareness of the need, and differing approaches to grieving family members).

182

Law & Order: Sonata for a Solo Organ (NBC television broadcast, Apr. 2, 1991).

183

Byrd & Clayton, *supra* note 19, at 20.

184

See generally *id.*

185

Washington, *supra* note 42, at 1F.

186

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See generally Scott Simon, Sale of Human Organs Thriving in Some Parts of the World (National Public Radio broadcast, Nov. 27, 1993), available in 1993 WL 9415778. According to Colonel Yuri Dubiyegen, "Organ Transplantation is the most profitable business in Russia and it will grow. Everyone knows that you can get away with abducting people for a kidney or for any other organ and they're convinced the criminals can get off scot-free." *Id.*; see also Anthony Boadle, Film Exposes Black Market in Body Parts From Humans, *Seattle Times*, Nov. 12, 1993, at A14 (illustrating that commercial documents obtained by the makers of a documentary entitled "The Body Parts Business" showed that one Russian company "sold 700 kidneys, hearts and lungs, 1400 livers, 18,000 thymus glands, 2,000 eyes and 3,000 pairs of testicles, which are used for rejuvenating creams.").

Christian Williams described the problem this way:

"The variation between legal systems has allowed abuse of the simplest method of organ procurement--organ sales from live donors. This system is generally poorly regulated and fraught with health risks to both the donor and recipient. Often, it is the poorer citizens of developing countries who are supplying organs for the members of the upper class who can afford them, either directly or through organ brokers. However, when the organ, like any other valuable commodity, cannot be bought, it is stolen resulting in flagrant violations of human rights."

Christian Williams, *Combatting the Problems of Human Rights Abuses and Inadequate Organ Supply Through Presumed Donative Consent*, 26 *Case W. Res. J. Int'l L.* 315, 316 (1994). The fear is public in some parts of the world: "a major newspaper has described the buying of kidneys from impoverished donors for transplantation in private hospitals in Western countries. Some donations were coerced, some for meager fees . . . It seems clear that . . . the less privileged can be exploited to improve the health of the more privileged." *Id.* at 322 n.33 (citations omitted). Christian Williams advocates presumed donative consent as a method of combatting the problems of human rights abuses and inadequate organ supply. *Id.* at 359.

187

Williams, *supra* note 186, at 359.

188

Id. at 358-59.

189

Rutherford, *supra* note 73, at 255. See generally Angela Y. Davis, *Surrogates and Outcast Mothers: Racism and Reproductive Politics*, in "It Just Ain't Fair": The Ethics of Health Care for

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African Americans 41-55 (Annette Dula & Sara Goering eds., 1994) (discussing the political and social ramifications for allowing surrogate motherhood).

190

“African Americans . . . are overrepresented [in industries such as] laundry and dry cleaning, tobacco manufacture, fabric mills, smelters, hospitals, and farmwork,” all of which involve toxic substances that have been linked to cancer. Rutherford, *supra* note 73, at 277.

191

499 U.S. 187 (1991). The Supreme Court decided that Title VII of the Civil Rights Act of 1964 prohibits an employer from excluding all women of child-bearing capacity from certain jobs, even if the employer's goal is to prevent possible damage to potential or developing fetuses. *Id.* at 211.

192

Rutherford, *supra* note 73, at 277-78.

193

Id. at 278.

194

Dana Hughes et al., Children's Defence Fund, *The Health Of America's Children: Maternal and Child Health data Book 10* (1989).

195

Children's Defense Fund, *Black And White Children In America: Key Fact 76* (1985).

196

Darci Elaine Burrell, *The Norplant Solution: Norplant and the Control of African-American Motherhood*, 5 *UCLA Women's L.J.* 401 (1995). “Norplant consists of six, match-sized, silicon tubes which release a steady stream of the synthetic hormone levnorgestill into the bloodstream to prevent pregnancy. The tubes are surgically inserted under the skin of a woman's arm and prevent conception for up to five years.” *Id.* at 401 (citation omitted).

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Donald Kimmelman, *Poverty and Norplant: Can Contraception Reduce the Underclass?*, *Phila. Inquirer*, Dec. 12, 1990, at A18; see, e.g., Claude Lewis, *Norplant Editorial Was Offensive: The Thrust of the Editorial was Aimed at the Black Underclass, Unjustly So*, *Phila. Inquirer*, Dec. 21, 1990, at A19. In the article, Kimmelman proposes to use Norplant to break the “cycle of inner city poverty--one of America's greatest challenges.” *Id.*

The main reason more black children are living in poverty is that the people having the most children are the ones least capable of supporting them. . . . All right, the subject makes us uncomfortable, too. But we're made even more uncomfortable by the impoverishment of black America and its effect on the nation's future.

Id.

198

David S. Coale, *Norplant Bonuses and the Unconstitutional Conditions Doctrine*, 71 *Tex L. Rev.* 189, 189-90 (1992); Dorothy E. Roberts, *Norplant's Threat to Civil Liberties and Racial Justice*, *N.J. L.J.*, July 26, 1993, at 20.

199

See, e.g., Tim Larimer, *High School Offers Birth Control Implant, Blacks Disagree on Merits of Program*, *Dallas Morning News*, Mar. 17, 1993, at A37. The Laurence Paquin High School, a predominantly Black school for pregnant girls or girls who have already had babies in Baltimore, Maryland, was the first school to offer Norplant to teens. *Sonya Live: Birth Control in Schools* (CNN television broadcast, Feb. 11, 1993).

200

Janet F. Ginzberg, *Compulsory Contraception as a Condition of Probation: The Use and Abuse of Norplant*, 58 *Brook. L. Rev.* 979, 979 (1992). For example, the Ohio legislature introduced a bill which would amend the definition of “child neglect” to include drug use during pregnancy and which would require women twice convicted of this crime to use Norplant. See Deborah Ann Bailey, *Comment, Maternal Substance Abuse: Does Ohio Have an Answer?*, 17 *U. Dayton L. Rev.* 1019, 1032-33 (1992) (discussing Ohio Rev. Code Ann. §§ 2151.03(A); 2919.221(B)(2)).

201

Burrell, *supra* note 196, at 404.

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202

Id. at 416 (citations omitted).

203

42 C.F.R. §§ 441.250-259 (1991) (sterilizations); 42 C.F.R. § 441.257 (1991) (informed consent); 42 C.F.R. § 441.258 (1991) (consent form requirements).

204

Laurie Nsiah-Jefferson, Reproductive Laws, Women of Color, and Low-Income Women, in Reproductive Laws For The 1990s 23, 46 (Sherrill Cohen & Nadine Taub eds., 1988).

205

But see Rutherford, *supra* note 73, at 267.

206

Id. (citing U.S. Dep't Of Health And Human Services, Public Health Services, Health Status Of Minorities And Low Income Groups 58 (1985) (reporting twenty-three percent of Black couples found infertile, compared to fifteen percent of White couples)).

207

Id. at 268 n.56.

208

Id. at 268 (citing Congressional Caucus For Women's Issues, The Women's Health Equity Act Of 1990 18 (1990)).

209

42 C.F.R. § 59.5(a)(1) (1995).

210

Rutherford, *supra* note 73, at 268.

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211

See generally Davis, *supra* note 189, at 41-55.

212

Rutherford, *supra* note 73, at 268-69. The surrogate mother carries the fetus to term. Most arrangements are governed by a contract whereby the surrogate mother is paid a sum of money and agrees to relinquish all parental rights to the child. *Id.* “The ‘rate’ is normally between \$10,000 and \$15,000, and the surrogate is paired with the infertile couple either through a fertility agency or privately.” *Id.* at 269.

213

Id. However, other women of color, particularly women from Third World countries, may be exploited. *Id.* A chain of clinics in India, Jordan, Pakistan, Egypt, Malaysia, Singapore, and Taiwan has been set up by U.S. and Australian entrepreneurs. In vitro fertilization clinics in Brazil, India, Malaysia, and Indonesia have been established particularly for sex predetermination. Janice G. Raymond, *Women as Wombs: International Traffic in Reproduction*, *Ms. Magazine*, May/June 1991, at 28, 31.

214

Rutherford, *supra* note 73, at 269-70.

215

The case of Anna Johnson, an African American woman who gave birth to the child of a white husband and an Asian wife, highlights the conflicts. The California Court of Appeals ruled that genetics was the determining factor in parenthood. *Anna J. v. Mark C.*, 286 Cal. Rptr. 369, 380-81 (Cal. Ct. App. 1991).

216

Rutherford, *supra* note 73, at 272 n.86 (citing Angela Y. Davis, *Women, Race And Class* 6-8 (1983) as stating:

Since slave women were classified as “breeders” as opposed to “mothers,” their infant children could be sold away from them like calves from cows. One year after the importation of Africans was halted, a South Carolina court ruled that female slaves had no legal claims whatever on their children. Consequently, according to this ruling, children could be sold away from their mothers

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at any age because “the young of slaves . . . stand on the same footing as other animals.”

(omission in original) (footnote omitted)).

217

Sellers-Diamond, *supra* note 161, at 424. As a result of Dr. Goodwin's announcement concerning the intent and the rationale of the Violence Initiative, he was dismissed as Director of the Alcohol, Drug Abuse, and Mental Health Administration and demoted to the position of Director of the National Institute of Mental Health. Under the new Clinton Administration, part of the Violence Initiative was canceled as a coordinated effort, amidst continuing doubts as to the integrity and legitimacy of the endeavor. *Id.* at 429.

218

See generally Department Of Health And Human Services, Report Of The Secretary's Blue Ribbon Panel On Violence Prevention (Jan. 15, 1993); Peter R. Breggin, M.D. & Ginger R. Breggin, *The Federal Violence Initiative: Threats to Black Children (and Others)*, 24 *Psychiatry Discourse* 8 (1993) (discussing the disadvantages of the federal Violence Initiative).

219

Sellers-Diamond, *supra* note 161, at 425 (citing Dr. Frederick K. Goodwin, Address at the Meeting of the National Mental Health Advisory Council 115, 117 (Feb. 11, 1992)).

220

Id. Dr. Goodwin, in one of the first introductions of the Violence Initiative, stated:

If you look, for example, at male monkeys, especially in the wild, roughly half of them survive to adulthood. The other half die by violence. That is the natural way it is for males, to knock each other off and in fact, there are some interesting evolutionary implications of that because the same hyperaggressive monkeys who kill each other are also hypersexual, so they copulate more to offset the fact that more of them are dying.

Now, one could say that if some of the loss of social structure in this society, and particularly within the high impact inner-city areas, has removed some of the civilizing evolutionary things that we have built up and that may be it isn't just the careless use of the word when people call certain areas of certain cities jungles, that we may have gone back to what might be more natural, without all the social controls that we have imposed upon ourselves as a civilization over thousands of years in our evolution.

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Id. at 426 (quoting Dr. Frederick K. Goodwin, Address at the Meeting of the National Mental Health Advisory Council 119-20 (Feb. 11, 1992)).

221

Sellers-Diamond, *supra* note 161, at 431 (citation omitted).

222

Id.

223

Id.

224

Id. at 453-54 (citation omitted).

225

Alexander Morgan Capron & Vicki Michel, Law and Bioethics, 27 Loy. L.A. L. Rev. 25, 25 (1993) (citation omitted); John D. Arras, Nancy Rhoden: Exploring the Dark Side of Biomedical Technology, 68 N.C. L. Rev. 835, 835 (1990); Sandra H. Johnson, The Changing Nature of the Bioethics Movement, 53 Md. L. Rev. 1051, 1051-52 (1994).

226

Capron & Michel, *supra* note 225, at 25.

227

Id. at 25, 27.

228

Id. at 28. “These-four principles are often referred to as the ‘Georgetown Mantra’ because they have been repeatedly articulated by scholars from the Kennedy Institute at Georgetown University.” Id. at 28 n.10. See generally Tom L. Beauchamp & James F. Childress, Principles of Biomedical Ethics (3d ed. 1989) (describing ethical principles that serve as the basis of analysis in the field of bioethics); The National Commission for the Protection of Human Subjects of

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Biomedical and Behavioral Research, The Belmont Report: Ethical Guidelines For The Protection Of Human Subjects Of Research (1978) (discussing and identifying basic ethical principles that should underlie the conduct of research involving human subjects); Susan M. Wolf, Shifting Paradigms in Bioethics and Health Law: The Rise of a New Pragmatism, 20 Am J.L. & Med 395 (1994) (analyzing the paradigm shifts under way in bioethics and health law, concentrating on what is gained by the shifts and the future of the disciplines). But see Albert R. Jonsen & Stephen Toulmin, The Abuse of Casuistry: A History of Moral Reasoning (1988) (asserting that agreement on the solution to bioethical problems comes not by deductive reasoning from general rules or principles, but from the analysis and classification of “case” and “circumstances”); H. Tristram Engelhardt, Jr., Bioethics and Secular Humanism: The Search for a Common Morality xi (1991) (asserting that we should establish a procedural ethic, based on respect of the freedom of the moral agents involved, even without establishing the correctness of any particular moral sense); but see also “It Just Ain't Fair”: The Ethics Of Health Care For African Americans (Annette Dula & Sara Goering eds., 1994); African-American Perspectives On Biomedical Ethics (Harley E. Flack & Edmund D. Pellegrino eds., 1992); Feminist Perspectives In Medical Ethics (Helen Bequaert Holmes & Laura M. Purdy eds., 1992) (discussing the role of ethics in the healing of medicine); Susan Sherwin, No Longer Patient: Feminist Ethics And Health Care (1992) (arguing that the “norms” of psychology are male-based and, as such, females are automatically seen as deviant); John D. Arras, Getting Down to Cases: The Revival of Casuistry in Bioethics, 16 J. Med. & Phil. 29 (1991) (asserting that ethical theory can still play a significant role in casuistical analysis); Albert R. Jonsen, Of Balloons and Bicycles--or--The Relationship between Ethical Theory and Practical Judgment, Hastings Center Rep., Sep.-Oct. 1991, at 14; Henry S. Richardson, Specifying Norms as a Way to Resolve Concrete Ethical Problems, 19 Phil. & Pub. Aff. 279 (1990).

229

Tom L. Beauchamp, Principles and Other Emerging Paradigms in Bioethics, 69 Ind. L.J. 955, 956 (1994).

230

See, e.g., Rebecca J. Cook, Feminism and the Four Principles, in Principles Of Health Care Ethics 193 (Raanan Gillon & Ann Lloyd eds., 1993) (discussing the different theories and distinctions within the feminist philosophy). But see Ruth Macklin, Women's Health: An Ethical Perspective, 21 J.L. Med. & Ethics 23 (1993) (defending the adequacy of the four principles for gender analysis).

231

Fred H. Cate, Emerging Paradigms in Bioethics: Posthumous Autonomy Revisited, 69 Ind. L.J.

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1067, 1072 (1994); Wolf, *supra* note 228, at 402.

232

Laurence Thomas, *The Morally Beautiful*, in *African-American Perspectives on Biomedical Ethics* 118, 123-25 (Harley E. Flack & Edmund D. Pellegrino eds., 1992).

233

Id.

234

Id.

235

Id.

236

Wolf, *supra* note 228, at 402.

237

Id.

238

Thomas, *supra* note 232, at 123-25.

239

Id.

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Wolf, *supra* note 228, at 402.

241

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Id. at 408; see also Susan M. Wolf, Health Care Reform and the Future of Physician Ethics, Hastings Center Rep., Mar.-Apr. 1994, at 28; Renée C. Fox, The Evolution of American Bioethics: A Sociological Perspective, in Social Science Perspectives on Medical Ethics 201 (George Weisz ed., 1990) (commenting on the similarities among the shifts in bioethics and those among the larger American scene); cf. generally Joseph A. Carrese & Lorna A. Rhodes, Western Bioethics on the Navajo Reservation: Benefit or Harm?, 274 JAMA 826 (1995) (explaining that Western bioethics, which emphasizes patient autonomy and self-determination, is generally considered negative and dangerous by Navajos: the Navajo way of thinking embraces positive thinking, beauty, harmony, and goodness); see also President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, The Ethical and legal Implications of Informed Consent in the Patient-Practitioner Relationship 74-76 (1982).

242

Beauchamp, *supra* note 229, at 956-57.

243

See generally Wolf, *supra* note 228, at 396-415 (asserting that the development of a rule-based approach has come to be known as “principlism,” or, deductive reasoning from a limited set of middle-level ethical principles, albeit with some reciprocal attention to the implications of the case at hand for those principles).

244

See Joanne Mills Garrett et al., Life-sustaining Treatments During Terminal Illness: Who Wants What?, 8 J. Gen. Internal Med. 361, 364 (1993) (discussing the relationships between patients' choices when they are terminally ill and their educational, demographic and cultural backgrounds).

245

Caralis, *supra* note 5, at 168.

246

Carl E. Schneider, Bioethics with a Human Face, 69 Ind. L.J. 1075, 1076 (1994); cf. Leon R. Kass, Practicing Ethics: Where's the Action?, Hastings Center Rep., Jan.-Feb. 1990, at 5 (discussing issues and problems that inherently have no answers); American Medical Association Judicial Council, Ethical Guidelines for Organ Transplantation, 205 JAMA 341, 341 (1968) (maintaining that the “decision whether to permit or to perform a transplantation procedure . . .

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must be a reasoned, intellectual decision, not an emotional decision.”); Arthur L. Caplan, Informed consent and Provider/Patient Relationships in Rehabilitation Medicine, in *If I Were A Rich Man Could I Buy A Pancreas?* 240, 245 (1992) (asserting that “[c]onsent must be voluntary and free--the product of deliberative reflection on all possible courses of action.”); Ezekiel J. Emanuel, M.D. & Linda L. Emanuel, M.D., Four Models of the Physician-Patient Relationship, 267 *JAMA* 2221, 2225 (1992) (suggesting that “[a]utonomy requires that individuals critically assess their own values and preferences; determine whether they are desirable; affirm, upon reflection, these values as ones that should justify their actions; and then be free to initiate action to realize the values.”).

247

See Schneider, *supra* note 246, at 1078-80; Peter H. Schuck, Rethinking Informed Consent, 103 *Yale L.J.* 899, 957-58 (1994) (noting that judicial cases evince little systematic interest in the consequences of the doctrine of informed consent; rather, courts tend to invoke the values of autonomy and improved decision-making and then analyze the implications of those values).

248

Paul S. Appelbaum, M.D. et al., Informed Consent: Legal Theory And Clinical Practice 46 (1987) (asserting that the law of informed consent rarely results in significant verdicts for plaintiffs since “few patients sue physicians in general, even fewer sue claiming lack of informed consent, and yet fewer prevail on that theory. . . .”); Paul C. Weiler, Medical Malpractice On Trial 13 (1991) (asserting that doctors are rarely sued: “[F]or every 8 potentially valid claims, only 1 claim [is] actually filed”); Barry R. Furrow et al., *Health Law: Cases, Materials And Problems* 187 (2d ed. 1991) (asserting that the existence of Good Samaritan legislation made no difference to the willingness of physicians to stop and assist); Arthur L. Caplan, Can Autonomy Be Saved?, in *If I Were A Rich Man Could I Buy A Pancreas?* 256, 261 (1992) (asserting that “[n]o more than 10 percent of the population has either a living will or a durable power of attorney” and “[s]imilarly dismal statistics are reported for the practices surrounding the issuance of DNR (do-not-resuscitate), DNI (do-not-intubate), and DNT (do-not-treat) orders in hospitals and nursing homes. . . .”); Russell S. Kamer, M.D. et al., Effect of New York State's Do-Not-Resuscitate Legislation on In-Hospital Cardiopulmonary Resuscitation Practice, 88 *Am. J. Med.* 108, 109-10 (1990) (asserting that the enactment of DNR legislation in the State of New York had little effect on the frequency of CPR and on the degree of patient or family involvement in the DNR decision).

249

See Robert C. Ellickson, *Order Without Law: How Neighbors Settle Disputes* 40-64 (1991) (noting that farmers and ranchers tended to settle disputes not based on the economically efficient

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solution, but on the value of neighborliness and reciprocity); Stewart Macaulay, Non-Contractual Relations in Business: A Preliminary Study, 28 Am. Soc. Rev. 55 (1963) (asserting that suppliers and purchasers in using contracts and the law of contracts did not conceive of themselves as using contract law even when, in legal terms, they were); cf. generally Carl E. Schneider, Lawyers and Children: Wisdom and Legitimacy in Family Policy, 84 Mich. L. Rev. 919, 940 (1986) (discussing whether “test case litigation” is the sensible way to foster the welfare of American children); Carl E. Schneider, Rethinking Alimony: Marital Decisions and Moral Discourse, 1991 B.Y.U. L. Rev. 197, 203-09 (discussing alimony and its purpose in today's world of no-fault divorce); Carl E. Schneider, Social Structure and Social Control: On The Moral Order of a Suburb, 24 Law & Soc. Rev. 875 (1990) (discussing the manner in which conflicts are resolved or are ignored in suburbs).

250

Autonomy is a principle of respect for the decision-making capacities of autonomous persons. *Cruzan v. Director, Missouri Dep't of Health*, 497 U.S. 261, 278 (1990) (holding that the right of autonomy extends to refusing life-prolonging procedures and to directing their withdrawal); *Schloendorff v. Society of New York Hosp.*, 105 N.E. 92, 93 (N.Y. 1914) (“Every human being of adult years and sound mind has a right to determine what shall be done with his own body; and a surgeon who performs an operation without his patient's consent commits an assault, for which he is liable in damages.”), overruled by *Bing v. Thunig*, 2 N.Y.2d 656 (N.Y. 1957); Beauchamp, *supra* note 229, at 956; George J. Annas, Life, Liberty and Death, 12 Health Mgmt. Q. 5, 5 (1990) (characterizing autonomy as “[t]he core legal and ethical principle that underlies all human interactions in medicine. . . .”); John A. Robertson, Posthumous Reproduction, 69 Ind. L.J. 1027, 1028 (1994) (maintaining that the right of autonomy extends to a principle for determining reproductive rights after an individual's death).

251

Nonmaleficence is a principle of avoiding the causation of harm to others. Beauchamp, *supra* note 229, at 956.

252

Beneficence represents a group of principles for providing benefits and balancing benefits against risks and costs. *Id.*

253

Justice is a group of principles for fairly distributing benefits, risks, and costs. *Id.*

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254

Edmund D. Pellegrino, Foreword to African-American Perspectives on Biomedical Ethics at v, vi (Harley E. Flack & Edmund D. Pellegrino eds., 1992); Wolf, *supra* note 228, at 397 (asserting that the bioethical pattern has been the downward application of principles with insufficient attention to the clinical context, the specific characteristics of the disputants (such as insurance status, race or ethnicity, and gender), and whether the rules will actually work in medical settings); see, e.g., Rand E. Rosenblatt, Dual Track Health Care--The Decline of the Medicaid Cure, 44 U. Cin. L. Rev. 643 (1975) (discussing the paradoxical reality that since doctors must survive from the income of their patients, the benefits of medicine will remain in the hands of the wealthy); Sylvia A. Law, American Civil Liberties Union, The Rights of the Poor 80-110 (1973). See generally Annette Dula, Bioethics: The Need for a Dialogue with African Americans, in "It Just Ain't Fair": The Ethics of Health Care For African Americans 11-23 (Annette Dula & Sara Goering eds., 1994) (discussing and criticizing the lack of critical discussion of cultural and social issues influencing bioethics).

255

Thomas, *supra* note 232, at 125.

256

Sanders, *supra* note 14, at 166; Dula, *supra* note 9, at 194.

257

See Dula, *supra* note 1.

258

See generally "It Just Ain't Fair": The Ethics of Health Care for African Americans, *supra* note 228.

259

See generally Alma Roberts, The Evolution of a Community Hospital: Improving Access to Ensure Political and Financial Viability, in "It Just Ain't Fair": The Ethics of Health Care for African Americans 195-200 (Annette Dula & Sara Goering eds., 1994) (highlighting the disparity between institutional resources spent on training physicians and those spent on the at-risk citizens the hospital has pledged to serve).

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260

See generally Brian Hertz, Toward Successful Urban Perinatal Health Care, in “It Just Ain't Fair”: The Ethics of Health Care for African Americans 201-07 (Annette Dula & Sara Goering eds., 1994).

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See generally Evelyn C. White & Shafia Mawushi Monroe, Interview: Lay Midwifery and the Traditional Child-Bearing Group, in “It Just Ain't Fair”: The Ethics of Health Care for African Americans 208-20 (Annette Dula & Sara Goering eds., 1994) (discussing a woman's experience about why and how she became a midwife).

262

See generally Margo Okazawa-Rey, Grandparents Who Care: An Empowerment Model of Health Care, in “It Just Ain't Fair”: The Ethics of Health Care for African Americans 221-23 (Annette Dula & Sara Goering eds., 1994) (discussing the role of grandparents who are assuming the primary responsibility of caring for their grandchildren).

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Dula, *supra* note 254, at 11-23.

264

Sanders, *supra* note 14, at 171 (citing Preston N. Williams, Ethics and Ethos in the Black Experience, 31 *Christianity & Crisis* 104 (1971)).

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