

# Genetics and African Americans

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Minorities are discriminated against in most societies. I categorize minorities as discriminated powerless subset populations of a state. Minorities include the Ainu and Koreans of Japan, Australian Aborigines, the Palestinians in Israel, the Catholics in Northern Ireland, Africans and Algerians in France, Africans and their descendants, and Asian Indians in Great Britain, and in the United States, African Americans, Hispanic groups, peoples of Asian-Pacific Islander, and American Indian-Alaskan Native origin, and poor people, almost everywhere.

## I. AFRICAN AMERICANS

The categorization of African Americans emanates from slavery, by the rule of hypodescent.<sup>1</sup> To perpetuate slavery into succeeding generations the offspring of black-white matings and their descendants were previously classified variously as Colored, Negro, Black, and an assortment of pejorative terms. In many other countries, African ancestry is not as stringent. An African American today could fly to Brazil and be classified into one of about forty divisions, from black to white. In Brazil, if a black person is educated or is wealthy he or she is categorized white. There is an old Brazilian aphorism, "Money Whitens." The African American could then fly to South Africa and be classified as Colored, or Black, or one of many tribal groupings, or even white. The African American could then fly to the Middle East and be categorized as Iranian, Lebanese, Saudi Arabian, Iraqi, etc., and then fly home and be African American once more.<sup>2</sup>

The development of techniques for the diagnosis of genetic disorders before and after birth stimulated a revolution in medical genetics. Prior to these discoveries, alternatives for the prevention of genetic disorders for couples at risk were genetic counseling, with the options of absti-

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<sup>1</sup> See generally JAMES E. BOWMAN & ROBERT F. MURRAY, JR., *GENETIC VARIATION AND DISORDERS IN PEOPLES OF AFRICAN ORIGIN* (1990).

<sup>2</sup> See *id.*

nence, contraception, sterilization, artificial insemination, adultery, and divorce. The initiation of a variety of tests for high frequency genetic disorders in the newborn and the general population was followed by education, testing, and counseling of high risk populations by private organizations, mandatory and voluntary state programs, and voluntary federal programs under the auspices of the National Sickle Cell Anemia Control Act.<sup>3</sup> Later, federal funding for genetic disorders was made possible under other acts as well.<sup>4</sup>

The first line of the National Sickle Cell Anemia Control Act stated "that sickle cell anemia is a debilitating, inheritable disease that afflicts approximately two million American citizens and has been largely neglected."<sup>5</sup> This legislation, which was to provide stimulus to research, education, testing, counseling and nationwide community programs in sickle cell disease and the development of Comprehensive Sickle Cell Centers and Program Projects for Research in Sickle Cell Disease also reflected the misinformation that was replete in the sickle hemoglobin educational literature of the early 1970s, and sometimes, today. Sickle cell anemia was confused with sickle cell trait. About 2,000,000 African Americans have sickle cell trait, not sickle cell anemia. The legislation also described the disease as deadly and tragic. On the other hand, some persons live long lives with very little illness. In short, the legislation emphasized the worst cases. It is also important to mention that this program emphasized voluntary cooperation.

In the National Sickle Cell Anemia, Cooley's Anemia, Tay-Sachs, and Genetic Diseases Act<sup>6</sup> it was emphasized that

[i]n order to preserve and protect the health and welfare of all citizens, it is the purpose of this title to establish a national program to provide for basic and applied research, research training, testing, counseling, and information and education programs with respect to genetic diseases, including sickle cell anemia, Cooley's anemia, Tay-Sachs disease, cystic fibrosis, dysautonomia, hemophilia, retinitis pigmentosa, Huntington's chorea, and muscular dystrophy.<sup>7</sup>

Ostensibly, the triad of education, testing, and counseling identified individuals and couples at risk so that they could make informed deci-

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<sup>3</sup> Pub. L. No. 92-294, 86 Stat. 136 (1972).

<sup>4</sup> See, e.g., National Sickle Cell Anemia, Cooley's Anemia, Tay-Sachs, and Genetic Diseases Act, Pub. L. No. 94.-278, 90 Stat. 470 (1976) (codified in scattered sections of 42 U.S.C.); Maternal and Child Services Block Grant of 1981, Pub. L. No. 97-35, 95 Stat. 818 (1981) (same).

<sup>5</sup> National Sickle Cell Anemia Control Act § 2 (a)(1).

<sup>6</sup> National Sickle Cell Anemia, Cooley's Anemia, Tay-Sachs, and Genetic Diseases Act § 402.

<sup>7</sup> *Id.*

sions about reproduction and health. These were noble objectives, but it is unlikely that Congress would have appropriated several hundred million dollars over the past twenty-five years for genetic education, screening, and counseling programs unless the lawmakers believed, or were led to believe, that there would be a significant reduction in the incidence of genetic disorders. An example is the Sickle Cell Anemia Control Act. The title is unfortunate because the control of sickle cell anemia could lead to unsavory mandatory policies.

## II. THE POOR

Timothy Smeeding and Barbara Boyd Torrey described the problems of poor children in rich countries, including Australia, Canada, Sweden, the United States, the United Kingdom, and West Germany.<sup>8</sup> The United States had the highest poverty rate among children and the second highest poverty rate among families with children. Not surprisingly, the poverty rate among black children was three times as high as among white children, and the poverty rate of Hispanics was double that of white children. Even so, the poverty rate among white children was 11.4%, a rate that was higher than that of all children in the other countries, except Australia. In Canada, the poverty rate of minority and non-minority populations, both 9.6%, was lower than that of white children in the United States alone.<sup>9</sup>

Almost daily, policy makers repeat the shibboleth that health care resources are scarce. Yes, health care resources are scarce, but only for the poor. Physicians have abrogated their responsibility to patients and allowed administrators and economists to impersonalize health care policy to such an extent that millions of Americans have limited or no access to health care, even in university medical centers. The federal government, the states, organized (disorganized) medicine, and university hospitals all blame each other for our abysmal health care system. Unfortunately, American human rights activists travel far and wide ferreting human rights violations abroad, and ignore our own human rights infamy: neglect of the health care plight of poor people in the United States. For example, in 1991, the United States ranked twenty-third in the world for infant deaths.<sup>10</sup> The African American neonatal, postneonatal, and infant death rates for Blacks was more than twice as high than

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<sup>8</sup> See generally Timothy M. Smeeding & Barbara Boyd Torrey, *Poor Children in Rich Countries*, 242 SCI. 873-77 (1988).

<sup>9</sup> See *id.* at 875-76.

<sup>10</sup> See NATIONAL CTR. FOR HEALTH STATISTICS, 1994 HEALTH UNITED STATES 93 (1995).

that of Whites.<sup>11</sup> In 1992, sixty-two to sixty-four percent of American Indian, Mexican American, and black mothers received early prenatal care. By contrast, eighty-four to eighty-eight percent of non-Hispanic white, Chinese, Cuban, and Japanese mothers received early prenatal care.<sup>12</sup> The United States is the most affluent country in the world. If a major thrust of genetic educational programs is directed to couples before marriage, what about children who are born out of wedlock? Unfortunately, this vital issue is studiously overlooked in most genetics programs.<sup>13</sup>

### III. EUGENICS

A weapon for discrimination of minorities has been eugenics—a political, economic, social, pseudoscientific, and scientific policy that espouses the reproduction of the “fit” over the “unfit,” positive eugenics, and discourages the birth of the “unfit,” negative eugenics.<sup>14</sup>

Galton introduced the word *eugenics* in nineteenth century Great Britain. He documented the concentration of genius and high achievement in his family and in families of his peers, and disparaged the intellectual abilities of the “masses,” and even peoples of Spain and France.<sup>15</sup>

The “fit” and “unfit” have been variously defined. The American Eugenics Movement in the 1920s targeted as “unfit” individuals with epilepsy, criminals, crippled and deformed peoples; persons who were mentally defective, or who had low intelligence; patients with communicable diseases such as syphilis, tuberculosis, or leprosy; alcoholics and drug abusers; poor people; and Eastern European immigrants to the United States. The Nazis marked Jews, Gypsies, and other so-called non-Aryan peoples, individuals who were mentally defective, and persons with incurable or mental illnesses—to name a few. In the heyday of eugenics, sterilization, infanticide, euthanasia, or a variety of “final solutions” were tools for the prevention or elimination of the “unfit.”<sup>16</sup>

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<sup>11</sup> See *id.* at 16.

<sup>12</sup> See *id.* at 17.

<sup>13</sup> See James E. Bowman, *Genetic Screening Programs and Public Policy*, 38 *PHYLON* 117, 132-36 (1977) [hereinafter Bowman, *Genetic Screening*]; James E. Bowman, *Is a National Program to Prevent Sickle Cell Disease Possible?*, 5 *AM. J. PED. HEMAT./ONCOL.* 367, 367-72 (1983) [hereinafter Bowman, *National Program*].

<sup>14</sup> See generally MARK M. HALLER, *EUGENICS: HEREDITARIAN ATTITUDES IN AMERICAN THOUGHT* (1963). See also KENNETH M. LUDMERER, *GENETICS AND AMERICAN SOCIETY: A HISTORICAL APPRAISAL* 7-45 (1972).

<sup>15</sup> See generally SIR FRANCIS GALTON, *HEREDITARY GENIUS: AN INQUIRY INTO ITS LAWS AND CONSEQUENCES* (1869).

<sup>16</sup> See HALLER, *supra* note 14, at 180.

But who are the “unfit” today, and how are they dealt with? Scientific advances in prenatal diagnosis—with the option for abortion—have broadened the “unfit” base to identify early in pregnancy fetuses with hereditary disorders such as Tay-Sachs Disease, neural tube defects, Down syndrome, sickle cell anemia, and cystic fibrosis. These fetuses are placed in the unfit category because abortion is offered as an option in genetic counseling. If they are not “unfit,” abortion would not be offered. There also have been repeated attempts to link genetics with abusers of alcohol or drugs and with perpetrators of violent crime since the beginnings of the American Eugenics Movement.

Recently, I introduced another form of eugenics: *passive eugenics*.<sup>17</sup> Passive eugenics is the societal acceptance of infant and maternal mortality rates in the United States that exceed that of any industrialized country; passive eugenics is an inequitable system of health care; passive eugenics is a society that countenances homeless mothers and children living on the streets in sub-zero weather while academicians make tenure and fortunes by investigating why the children have lower test scores and achievement than their classmates who live in middle-class homes and have access to books, parental assistance guidance for complex homework, and computers with access to the Internet.

Further, in order to excuse our disgraceful social and health care system we parrot a recurring shibboleth: “Health Care Resources Are Scarce.” But this catchphrase is incomplete. “Health Care Resources are Scarce *For Poor People*.” A society that accepts passive eugenics will also approve the discouragement of the birth of children with “preventable” genetic disorders. The slippery slope from passive to active eugenics may be an inexorable continuum.

Discrimination is cryptic, even in the field of ethics. For example, minorities should not accept utilitarianism<sup>18</sup> as a philosophy, no matter how noble sounding, for it would subject them to the doctrine of “the greatest good for the greatest number.” Minorities would be foolish to embrace utilitarianism.<sup>19</sup> But here is the dilemma: To reject this concept would be to negate marriage laws, compulsory vaccination for communicable diseases, seat belt laws, and most public health measures.

#### IV. MANDATORY STERILIZATION

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<sup>17</sup> See James E. Bowman, *Genetics and Racial Minorities*, in 2 *ENCYCLOPEDIA OF BIOETHICS*, 976-84 (Warren Thomas Reich ed., 1995).

<sup>18</sup> See generally JOHN STUART MILL, *UTILITARIANISM* (4th ed. 1871)

<sup>19</sup> See J.J.C. SMART & BERNARD WILLIAMS, *UTILITARIANISM: FOR AND AGAINST* 105 (1973).

To compound the problem, Philip Reilly<sup>20</sup> asserted that at least thirteen states still have mandatory sterilization laws on their books. The Supreme Court upheld these sterilization laws in the landmark decision of *Buck v. Bell*,<sup>21</sup> which legalized mandatory sterilization for eugenic reasons. During this time, Adolph Hitler and his colleagues were laying the groundwork for National Socialism with the American Eugenics Movement as a model.<sup>22</sup> In their rush to judgment, it is likely that those who were after Carrie Buck's fallopian tubes were also guided by prejudice against the poor. Dr. Laughlin's expert testimony in Virginia against Carrie Buck substantiates this premise. Laughlin asserted, "These people belong to the shiftless, ignorant, and worthless class of anti-social whites of the South."<sup>23</sup> The courts would not have sought the fallopian tubes of an affluent woman.

#### V. THE POLICE POWER OF THE STATE

The police power of the state is based on utilitarian ethics in that the Supreme Court in *Munn v. Illinois*<sup>24</sup> supported a fundamental precept of both democratic and totalitarian societies: the private interests of the individual must be subservient to the public interest. This is why Carrie Buck lost her fallopian tubes to the State. The threat of eugenics today lies not in blatant criminal behavior like that associated with Nazi Germany, but in subtle scientific, social, and political precepts. In fact, interestingly, some of the court decisions that lead to eugenics are based on liberal views of autonomy, and the right to privacy as found in *Roe v. Wade*.<sup>25</sup>

A poignant article by Herbert Aptheker<sup>26</sup> was replete with tragic examples of sterilization of poor blacks. In July 1973, Mr. and Mrs. Lonnie Relf, complained to the Southern Poverty Law Center of Montgomery, Alabama, that two of their daughters, ages twelve and fourteen, had been surgically sterilized without their knowledge. Another daughter, age seventeen, had escaped sterilization only because she had resisted. These three children had also been injected with an experimental drug to prevent conception. When tests found the drug to be carcinogenic,

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<sup>20</sup> See generally PHILIP R. REILLY, *THE SURGICAL SOLUTION: A HISTORY OF INVOLUNTARY STERILIZATION IN THE UNITED STATES* (1991).

<sup>21</sup> 274 U.S. 200 (1927).

<sup>22</sup> See REILLY, *supra* note 20.

<sup>23</sup> James E. Coogan, *Eugenic Sterilization Holds Jubilee*, CATH. WORLD, Apr. 1953, at 45.

<sup>24</sup> 97 U.S. 200 (1876).

<sup>25</sup> 410 U.S. 113, 152-62 (1973) (discussing an individual's right of privacy).

<sup>26</sup> See Herbert Aptheker, *Sterilization, Experimentation and Imperialism*, 53 POL. AFF. 37 (1974).

authorities in the federal government ordered the investigation stopped. The Montgomery officials then ordered sterilization of the children.

Other cases came to light. Aiker County Hospital records showed that of thirty-four deliveries paid for by Medicaid in 1972, eighteen included sterilization; all eighteen were black women, and all eighteen were performed by the same physician who stated that his policy was to require sterilization after a woman on welfare had had three children.

Elyce Zenoff Ferster asserted that there is indeed considerable support for the restriction of costs of welfare by involuntary sterilization.<sup>27</sup> Ferster concluded with a statement that should serve as a reminder to those who maintain that public policy will not take this route:

Proponents of involuntary sterilization, both in the past and today seem to imply that those who oppose these laws place the right of procreation above the welfare of society. It is possible that the day will come when this statement is accurate. The hereditary nature of these conditions may be established, or all reasonable attempts at improving the environment and rehabilitation of the disabled may fail, or food and air shortages may become so severe that there might not be enough to bear the burden of any further growth in population, then, there will be a choice between sterilization and the rights of the individual. If the time comes when any of these conditions exist, and if efforts at birth control fail, and if we can decide who should be sterilized and who is qualified to make this decision, then perhaps legislation authorizing involuntary sterilization could be justified.<sup>28</sup>

The police power of the state also invades marriage and the family. Family definitions and marriage restrictions also open the door to eugenics, because many of the prohibitions against marriage—particularly those against consanguineous mating—are far less defensible, genetically, than the mating of carriers with identical traits for genetic disorders. The banning of consanguineous mating facilitates the interdiction of mating of carriers for sickle cell disease, Tay-Sachs disease, cystic fibrosis, and eventually the mating of carriers of several thousand genetic disorders, once the techniques for early diagnosis in utero are developed.

## VI. HEALTH CARE INEQUITY

As noted earlier, laws and practices with eugenic implications are often designed for other purposes. For instance, universal health care may operate to discourage the birth of children with genetic defects, because of their perceived burden on public funds. Limits to state support

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<sup>27</sup> See generally Elyce Zenoff Ferster, *Eliminating the Unfit—Is Sterilization the Answer?* 27 OHIO ST. L.J. 591 (1966).

<sup>28</sup> *Id.* at 624-25.

of children born of mothers who are on welfare is a policy that has eugenic implications for poor mothers who repeatedly bear children with "preventable" genetic disorders. Scientific advances in genetics create a fertile ground for eugenics, because inequities in the delivery and costs of health care have led to plans for additional rationing of health care under the rubric of broadening the base of our market health care system to include millions of Americans who are merely bystanders to decent preventive health care and health. If health care resources are indeed scarce for poor people, economic pressures to reduce health care costs may (will) one day restrict the birth of children with "preventable" severe genetic disorders by indirect coercion or by mandatory legislative and court prohibitions. Accordingly, because *passive eugenics* is public policy, *negative eugenics* may (will) reenter public policy under the guise of "limited health care resources."

#### VII. WRONGFUL BIRTH; WRONGFUL LIFE

Once scientific advances become part of the public domain, the courts have invariably supported their use, and expect that patients will be made aware of them. Accordingly, failure to inform patients of medical advances has been a source of litigation in the form of wrongful birth and wrongful life suits. One of the first wrongful life cases, *Gleitman v. Cosgrove*,<sup>29</sup> rejected a woman's plea that she would not have borne a child blinded by rubella if she had known that rubella early in pregnancy could affect the fetus. The reason for the rejection of her argument was that abortion was illegal, and therefore the physician was under no obligation to suggest an illegal act. Interestingly, even though the state is under no obligation to fund abortions for poor women,<sup>30</sup> the state will generally pay for voluntary (indirect coercive) sterilization for poor women. Accordingly, sterilization as an option to prevent future children with genetic disorders now has a more scientific rationale, but will disproportionately, as always, be limited mainly to poor women.

Not surprisingly, because risk analysis is a major factor in insurance and employment, recent advances in genetic prediction may be taken into account in considerations for health, life insurance, and employability. On the other hand, employers and insurance companies only reflect the American market system. Even the Americans with Disabilities Act of 1990<sup>31</sup> does not restrict insurers or any agents that administer benefit

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<sup>29</sup> 49 N.J. 22, 227 A.2d 689 (1967).

<sup>30</sup> See *Harris v. McRae*, 448 U.S. 297, 306-11 (1980).

<sup>31</sup> 42 U.S.C. § 11201 et seq. (1995).



plans from underwriting risks that are based on or not inconsistent with state law.<sup>32</sup>

Interestingly, "Right to Life," or Anti-Choice, and the opposing Pro-Choice movements may serve as a needed balance. Paradoxically, these opponents serve as buffers to eugenics. The Anti-Choice movement opposes abortion, a modern tool to eliminate the "unfit," but the Pro-Choice movement fosters autonomy and freedom for women to choose or not choose abortion. If autonomy prevails, society will not be able to mandate abortion.

Jews, on the other hand, know their history and its tragic consequences in Nazi Germany. All programs for Tay-Sachs disease were voluntary, and directed by experienced geneticists, with the cooperation of rabbis and the community.<sup>33</sup> There have never been recommendations for either federal or state mandatory programs for Tay-Sachs Disease. Today, however, mandatory newborn screening for sickle hemoglobin is now the law in over thirty-nine states in order to decrease morbidity and mortality early in life from pneumococcal disease by the early introduction of prophylactic penicillin.<sup>34</sup>

#### VIII. BIRTHS OUT OF MARRIAGE

Even though abortion is now available on demand, births outside of marriage are a major social problem. In 1970, 5.5% of all white births were to unmarried women and 37.5% of all black births were to unmarried women. In 1992, 22.6% of all white births were to unmarried women and 68.1% of all black births were to unmarried women.<sup>35</sup>

According to vital statistics from the State of Illinois, in some communities in Chicago the out-of-wedlock birth rate approaches and even attains 100%. Welfare regulations that prohibit paying welfare to couples living together contribute to these vital statistics. The increase in female-headed families has disastrous social and economic consequences; these families are much more vulnerable to poverty than are other families.

It would appear that, at the present time, the black minority population is most reluctant to accept prenatal diagnosis and abortion for sickle

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<sup>32</sup> See Marvin R. Natowitz et al., *Genetic Discrimination and the Law*, 50 AM. J. HUM. GENETICS, 465, 467 (1992).

<sup>33</sup> See Michael M. Kaback & John S. O'Brien, *Tay-Sachs: Prototype for Prevention of Genetic Disease*, HOSP. PRAC., Mar. 1973, at 113-14.

<sup>34</sup> See Marilyn H. Gaston et al., *Prophylaxis with Oral Penicillin in Children with Sickle Cell Anemia* 314 NEW ENG. J. MED. 1593-99 (1986).

<sup>35</sup> See NATIONAL CENTER FOR HEALTH STATISTICS, *supra* note 10, at 75.

cell disease.<sup>36</sup> The reasons have not been documented; however, education, religion, suspicion of the health care system, are all conjectural, and not supported by other statistics. In 1990, the National Center for Health Statistics recorded that in the white population there were 17.5 abortions in 1973 and 30.0 abortions in 1987 per 1000 live births. Thirty-six Blacks were classified in the "all other" group and undoubtedly consisted the majority of this group. In this population there were 28.9 abortions per one thousand live births in 1973 and 55.7 abortions in 1987.<sup>37</sup> These figures are interesting, because it would be odd if black women abort unaffected fetuses at a higher rate than do white women, but forgo aborting fetuses with sickle cell disease.

#### IX. THREE PLAGUES: POVERTY, DRUG ADDICTION, AND AIDS

A *New York Times* editorial<sup>38</sup> outlined three plagues that blight the South Bronx in New York City: poverty, drug addiction, and AIDS. Among emergency room patients tested at Bronx Lebanon Medical Center, twenty-three percent were infected with the AIDS virus. In one South Bronx District, one in twenty-five pregnant women carried the virus, and about one-third to one-half of their babies will be infected with an incurable disease that will cost upwards of \$100,000 per affected child, with death the end result. The people of the South Bronx are mainly Black or Hispanic, and poor.

Any genetics program in the Black and Hispanic community that does not take these social, economic, and health factors into consideration will have almost no prospect for success. Unfortunately, it is unlikely that we will legislate mandatory equitable education, decent housing, health care for all, and full employment to alleviate the predicament of the poor. If we ask poor women to cooperate in community genetics programs, and disallow universal prenatal care, equitable health care delivery, and disregard the appalling social and economic conditions in this country, then we are conspirators in health care deceit.

#### X. COUNSELING

All publications in genetic counseling emphasize the importance of education of the community before genetic screening is instituted, accu-

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<sup>36</sup> See M. Catherine Driscoll et al., *Prenatal Diagnosis of Hemoglobinopathies: The Experience of the Columbia University Comprehensive Center for Sickle Cell Disease*, 40 AM. J. HUM. GENETICS 548-58 (1987); Peter T. Rowley et al., *Prenatal Screening for Hemoglobinopathies. I. A Prospective Regional Trial*, 48 AM. J. HUM. GENETICS 439-45 (1991).

<sup>37</sup> See NATIONAL CENTER FOR HEALTH STATISTICS, *supra* note 10, at 79.

<sup>38</sup> See *Three plagues*, N.Y. TIMES, Feb. 23, 1989, at A22.

rate testing, and counseling that is sensitive to the racial, class, and religious characteristics of the community.<sup>39</sup> Whenever possible, counselors should be of the same ethnic group as the counselees. Language is important. Today, efforts are made to produce educational and counseling material in the language of the counselees. This may be impossible, particularly when dealing with communities such as those from Vietnam and Laos, where a multiplicity of languages may be represented.

#### XI. ABORTION INEQUALITY

The expanding field of prenatal diagnosis could not have been developed without the landmark Supreme Court decision of *Roe v. Wade*,<sup>40</sup> which established the right for a woman to have an abortion under certain conditions. This decision was preceded by *Griswold v. Connecticut*,<sup>41</sup> which established the right *not* to procreate. Although abortion is legal, the Supreme Court decisions of *Maher v. Roe*<sup>42</sup> and *Harris v. McRae*<sup>43</sup> affirmed that even if abortion is legal—under certain conditions—the state has no obligation to pay for abortion.

Justices Marshall, Blackmun, and Brennan dissented in *Maher*. I quote in part Justice Brennan's poignant dissent:

But a distressing insensitivity to the plight of impoverished pregnant women is inherent in the Court's analysis. The stark reality for too many, not just "some," indigent women is that indigency makes access to competent licensed physicians not merely "difficult" but "impossible." As a practical matter, many indigent women will feel that they have no choice but to carry their pregnancies to term because the State will pay for the associated medical services, even though they would have to have abortions if the State had also provided funds for that procedure. This disparity in funding by the State clearly operates to coerce indigent pregnant women to bear children they would not otherwise choose to have, and just as clearly this coercion can only operate upon the poor, who are uniquely the victim of this form of financial pressure.

Mr. Justice Frankfurter's words are apt:

To sanction such a ruthless consequence, inevitably resulting from a money hurdle erected by the State, would justify a latter-day Anatole France to add one more item to his ironic comments on the 'majestic equality' of the law. The law, in its majestic equality, forbids the

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<sup>39</sup> See generally BOWMAN & MURRAY, *supra* note 1.

<sup>40</sup> 410 U.S. 113 (1973).

<sup>41</sup> 381 U.S. 479 (1965).

<sup>42</sup> 432 U.S. 464 (1977).

<sup>43</sup> 448 U.S. 297 (1980).

rich as well as the poor to sleep under bridges, to beg in the streets, and to steal bread.<sup>44</sup>

An editorial in the *New York Times* stated that the Department of Health and Human Services issued regulations banning federal funds to clinics that offer abortion counseling.<sup>45</sup> The editorial pointed out that should these rules take effect, four million women—mainly poor women—who depend on federally supported family planning clinics, would suffer.<sup>46</sup> These women would be denied access not only to abortion, but also to medical information that would keep them from becoming pregnant. The editorial asked how can a physician, forbidden under the regulations even to mention the word abortion, help a woman make an informed choice about family planning.<sup>47</sup> Further, the editorial questioned the humanity of the regulations stating, “how cruel that a poor woman can’t be told that an abortion is a legal option—and given a referral if she requests one—compared with the woman who can afford a private doctor.”<sup>48</sup> It was also asserted that in the United States, there are two kinds of family planning counseling: one for the affluent and the middle class; and one for the poor.

Public funds are spent on research in genetics and for genetic education, screening and counseling programs for intractable disorders, many of which can only be prevented by prenatal diagnosis and selective abortion. Public monies are also spent on research to improve techniques of prenatal diagnosis, with a potential end result of selective abortion. Poor patients are encouraged by state and federal genetics programs to participate; they are led to the brink, and then must be told that support ends here. Ironically, the poor are neglected, but scientists are not. If *Roe* is overturned, or if abortion is limited to cases of rape, incest, or to save the life of the mother, the middle and upper class will either experience what the poor have had to endure—or fly to Sweden, as they did before *Roe*.

## XII. NEWBORN SCREENING

Although the medical indications for newborn screening for sickle cell disease are indisputable, newborn screening programs should encompass more than the ascertainment of newborns with sickle cell disease. Family studies, counseling, provisions for health care for infants with

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<sup>44</sup> *Maier*, 432 U.S. at 483 (Brennan, J., dissenting) (quoting *Griffin v. Illinois*, 351 U.S. 12, 23 (1956) (Frankfurter, J., concurring)).

<sup>45</sup> See *The Importance of Dr. Sullivan*, N.Y. TIMES, Dec. 23, 1988, at A38.

<sup>46</sup> See *id.*

<sup>47</sup> See *id.*

<sup>48</sup> *Id.*

sickle cell disease, and options for prenatal diagnosis on subsequent pregnancies should be offered. Concurrent with such programs, holistic health care should be a major goal. Guidelines should be initiated for the equitable use of genetic technology on a voluntary basis. Mandatory genetics legislation should be replaced by voluntary legislation in order to insure that newborn screening is not followed by putative legislation to discourage the birth of children with preventive genetic diseases. Along these lines, most marriage restrictions should be repealed in order to remove these as precedent or models for the prevention of the birth of children with genetic disorders.

The development of techniques for newborn screening and for prenatal diagnosis of sickle hemoglobin and other hemoglobinopathies will have a profound effect on health public policy to a greater extent than did mass population testing that was initiated in the early 1970s. There is an old aphorism: "One cannot do one thing." Accordingly, the public policy of newborn screening will have many consequences. I cannot anticipate all of the effects of such a policy, but some aftermaths may be predicted with near certainty.

Legislation, court decisions, state and federal genetics programs, and scholars in the social sciences, the humanities, law, medicine, and genetics all support discoveries in genetics that now facilitate genetic testing, prenatal diagnosis, and selective abortion of fetuses with genetic and other disorders, artificial insemination, and in vitro fertilization. Arguments for and against these procedures are reminiscent of debates about the utilization of the limited tools of the old eugenics to prevent the birth of children who were considered to be physically, mentally, or socially defective.

The medical indications for newborn screening for sickle hemoglobin are indisputable. The principal questions are, "how?" and "what follows?" The resolution of these questions have ethical, legal, and medical implications, all of which are interrelated.

Today, we are discussing the merits of newborn screening for sickle cell disease, an entity that affects about one out of 400 to 500 black newborns, and the consequent salvage of precious lives. On the other hand, it is likely that sickle cell disease contributes only a minuscule amount to these appalling statistics. Hence, when we initiate newborn screening for sickle cell disease, we must dissociate ourselves from self-interest and work for a holistic policy. If we ask poor mothers to participate in newborn screening programs and do not fight for universal prenatal care, equitable health care delivery, education, adequate housing, and food, then we are co-conspirators in health deception.

Let us return to newborn screening. Some current programs operate under the principle that the purpose of newborn screening is medical and that the follow up of carriers and of other members of the family will dilute the effort and compromise the primary purpose of the program. Newborn screening for sickle cell disease and for other hemoglobinopathies should be followed by the encouragement of the testing of other family members when both the disease and the carrier state is found. To ignore carriers is to miss undetected sickle cell disease in other members of the family or in future children. Further, such a policy denies the parents' right to know and abrogates their right not to have another child with sickle cell disease. Newborn screening should be accompanied by testing other members of the family and also by offering prenatal diagnosis in a future pregnancy. Thus, newborn screening leads to a program of prenatal diagnosis for sickle cell disease.<sup>49</sup> This leads to further conundrums.

It is not uncommon for women to have children from several mates. Often times, the putative mate refuses to cooperate when his mate is found to have a hemoglobin variant. Because the woman is autonomous with respect to her own body—or we hope she is—the woman should be offered the option of prenatal diagnosis without testing the mate. The odds that a black woman in the United States with sickle cell trait, for example, will have a child with sickle cell anemia is one in forty—provided that the mate is black. These odds are eight times greater that a pregnant woman age thirty-five will have a child with Down syndrome. This prenatal option is not intended to equate sickle cell disease with Down syndrome.

Newborn screening will have population consequences. Discrimination against persons with sickle cell trait has not been abolished. Some of our best potential college and professional athletes have sickle cell trait.<sup>50</sup> Education programs for physicians, education in the schools, and community education should be intensified; otherwise, many future athletic champions will not come to fruition.

With the exception of a few digressions, technological advances in sterilization, contraception, abortion, genetic carrier identification, genetic therapy, or prophylaxis has been followed by general public acceptance, even though in some situations a minority or a considerable segment of our society has been outraged. The courts have frequently exercised the common law of malpractice to ensure that physicians and other health workers make available to their patients recent advances in

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<sup>49</sup> See generally Bowman, *Genetic Screening*, *supra* note 13.

<sup>50</sup> See *id.* at 130.

health technology, including the prevention of the birth of children with genetic defects.

Once it becomes general knowledge that the birth of children with certain genetic disorders is preventable, other members of the family, and the community, may question the wisdom of ignoring medical advances and concentrating on newborn screening and prevention of morbidity and mortality. The regulation of reproduction by the state for economic reasons does not have to be so crude as to require mandatory abortion or prenatal diagnosis. Other indirect coercive means are available.

In *Dandridge v. Williams*,<sup>51</sup> the Court upheld the legality of a maximum welfare grant imposed by the State of Maryland. This regulation restricted total Aid to Families with Dependent Children (AFDC) to a maximum of \$250 per month, no matter how large the family.<sup>52</sup> Thus, poor women in Maryland—and now, everywhere, if the state so chooses—can either elect to have additional children who will be wards of the state, or be restricted to the unsavory options of abstinence, sterilization, or abortion. Even if a poor woman meticulously practices contraception, contraceptive failure can be penalized. But unaffected children cost the state far less than children with sickle cell disease and other serious genetic disorders. If the state can place limits on the birth of poor unaffected children by indirect coercion, it can also place limits on the birth of children with serious genetic disorders. Herbert Aptheker, in a discussion of this decision, pointed out that at least fourteen states are considering legislation that would require women on welfare to submit to sterilization.<sup>53</sup> If the highest Court of the land upheld restrictions on welfare payments for healthy children, an extension of this precedent to include the restriction of the birth of poor children with severe genetic disorders—which are far more costly to the state—by at least covert duress is self evident. Thus, unfortunately the specter of *Dandridge* may haunt us as health care costs escalate.

Nevertheless, even though eugenics has thrived since at least the times of ancient Greece, I will not be fashionable and disparage the development of genetic technology nor will I be so foolish as to flail at windmills and concoct policies to limit scientific inquiry.

As more and more women enter the marketplace, family sizes are decreasing to such a extent that in the middle and upper income groups, the number of children is below the replacement level. Women who have fewer children will want to ensure—if at all possible—that their children

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<sup>51</sup> 397 U.S. 471 (1970).

<sup>52</sup> See *id.* at 474.

<sup>53</sup> See Aptheker, *supra* note 26, at 44

will be healthy. This is particularly true of the many working women who have their first child in their early thirties.

What can our society do in the face of exploding genetic technology? Interestingly, once genetic defects are discovered, many states with mandatory newborn screening legislation make no provisions for care of the affected children. We must not be so callous. Newborn screening programs for sickle cell disease must not replicate this shortsighted health policy.

The following public policy considerations are offered as guidelines for newborn screening for sickle cell disease and other genetic disorders:

(1) Develop procedures for the equitable use of genetic technology by all who wish to participate—on a voluntary basis;

(2) Replace state mandatory genetics legislation by state voluntary genetics laws, modeled on the states that already have successful programs. This goal could be urgent, because if it is not instituted, mandatory prenatal screening programs could be instituted with, perhaps, far more justification than mandatory newborn screening programs;

(3) Support the efforts of voluntary organizations, such as sickle cell anemia programs, cystic fibrosis associations, Down syndrome groups, and particularly mental deficiency programs in the provision of counseling, support and care. Counseling programs should not be centralized; they should be associated with the health care facilities of the patients and their families;

(4) Sponsor educational programs for eugenicists, medical geneticist, right to life groups, and religious organizations on the consequences of monistic policies that serve only their own vested interests. Emphasize the importance of accommodation in a pluralist society;

(5) Ensure that all newborn screening programs be accompanied by the care of the persons who are found to be affected; and

(6) Repeal restrictions on marriage. Although this recommendation may probably cause considerable consternation, if it is not done, marriage restrictions of persons with genetic traits and diseases could follow with far more justification than bans on first cousin marriages. The risk that first cousins will have a child with a severe genetic disorder is much lower than that of the mating of carriers for recessive genetic disease.

Others found that in a prenatal diagnosis program obstetricians were reluctant to provide education before pregnant women were tested for hemoglobins.<sup>54</sup> Such practice is contrary to accepted practice in genetic programs. It is paternalistic, it denies autonomy of the pregnant woman, it places her at risk for stigmatization for employment, life and health in-

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<sup>54</sup> See generally Rowley et al., *supra* note 36, at 440.



surance, without her consent. On the other hand, in the real world of practice in a busy obstetrician's office, other means of counseling may have to be found, such as ethnic relevant educational materials, recordings, and office or home videos.

Unfortunately, poverty, lack of access to contraceptive information, and an escalating out-of-wedlock birth rate in the black community are ignored in federal and community programs, and in pre-marital sickle hemoglobin state testing mandates. Undoubtedly, and understandably, out-of-wedlock births are cautiously dealt with by scientists and geneticists, but the social science literature, and the media are replete with information that is ignored in the planning of most genetics programs. Why? I speculate that the specter of racism has been raised so often that many scientists do not wish to become involved in such a controversy. But this is conjecture. Nevertheless, the human genetics literature rarely mentions the dilemma of out-of-wedlock births and their effect on human genetics programs. And this is tragic. Genetics programs are usually constructed on the basis of the classical description of the family and the testing of couples before marriage; the real world is ignored. A program that depends on the cooperation of putative fathers in such a situation places the poor pregnant woman who does not wish to have a child with sickle cell disease in an untenable position. But this argument also leads to the specter of eugenics. Therefore, no matter what the decision, the slippery slope is everywhere.

Will we go as far as China? China acted to decrease the incidence of children with severe genetic disorders through the Law of the People's Republic of China on Maternal and Infant Health Care.<sup>55</sup> First, China, unlike the United States, mandates that mothers and infants receive medical and health care services.

Marriage is allowed for couples with a genetic disease of a serious nature only if the couples agree to take long-term contraceptive measures, or to be sterilized.<sup>56</sup> When applying for marriage, the couples must produce their pre-marital check-up certificates.<sup>57</sup> If a physician detects or suspects that a married couple in their child-bearing age have a genetic disorder of a serious nature, the physician shall give medical advice to the couple, and the couple is expected to take measures in accordance with the physicians advice.<sup>58</sup> The physician is expected to give medical

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<sup>55</sup> LAW OF THE PEOPLE'S REPUBLIC OF CHINA ON MATERNAL AND INFANT HEALTH CARE, No. 33 (1994) (China). I thank Professor Greeley of Stanford University Law School for providing a copy of this document.

<sup>56</sup> See *id.* ch. 2, art. 10.

<sup>57</sup> See *id.* art. 12.

<sup>58</sup> See *id.* ch. 3, art. 16.

advice for a termination of pregnancy, which is performed free of charge.<sup>59</sup>

Look elsewhere for easy solutions for the conundrums that are inevitable with genetic discovery. I will state the problems, and often I will interject solutions. But today's sense is often tomorrow's nonsense. Proponents and opponents of various strategies to limit reproduction of the "unfit" line up in bewildering combinations. Individual freedom and autonomy often is pitted against the welfare of the state (the public interest). Open and disguised movements for fundamentalist religious hegemony, ignorance, paternalism, vested interests of the health professions, scientific entrepreneurs, and do-gooders and well-meaning people may be more difficult to challenge than organizations and individuals with blatant eugenic objectives.

The prospects of eugenics are anathema to most geneticists and ethicists. Nevertheless, consider the plight of poor women in the United States. The doctrine that the public interest of individuals must be subservient to the state, mandatory sterilization laws, the legalization of abortion, the shibboleth that health care resources are scarce, state sanctions on unmarried mothers, the widening gap between the haves and the have-nots, developments in prenatal diagnosis, spectacular advances in deciphering the human genome, and pressures from insurance companies on individuals and corporations lead inexorably to state, community, and even familial pressures to restrict the birth of children with severe genetic disorders, and most specifically, members of powerless minorities.

Today, however, we are concerned not only with those with genetic disease who may be stigmatized as unfit but also with individuals who carry a single dose (carriers) of a genetic defect, which causes little if any effect. Because we all have at least five recessive genes, all of us are at risk for having "unfit" children. Five recessive genes may, however, be just the tip of the iceberg. When the human genome is mapped, many more potentially harmful genes—recessive and otherwise—will be unveiled in each of us. Consequently, in this day of rapid advances in genetics, we all are potentially able to pass "unfit" disorders to the next generation. Because we are all now in the same boat, scientific advances in the understanding of the human genome *may* be one of the best defenses against subjecting minorities to eugenic discrimination. We rarely discriminate against those who are "like ourselves."

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<sup>59</sup> See *id.* art. 18.