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From Eugenics to Medical Genetics

Sheldon Reed coined the expression "genetic counseling" in 1947, the same year he succeeded Clarence P. Oliver as Director of the University of Minnesota's Dight Institute for Human Genetics. In reflections written more than a quarter-century later, Reed noted that the term had occurred to him "as a kind of genetic social work without eugenic connotations." Sharply distinguishing the aims of eugenics and counseling, he explained that whereas the former promotes the interests of the larger society, the latter serves the interests of individual families—as families perceive them. Reed never denied that he or other postwar medical geneticists were concerned with population improvement. But he maintained that counseling served a different purpose. Commenting on the history of the Dight Institute, Reed asserted: "There were certainly no attempts to benefit society as a whole in dealing with these families. This was not thought of as a program of eugenics."¹

The historical record suggests a rather more complex story. In the 1950s and 1960s, genetic counseling was characterized by most of its practitioners as an extension of eugenics. Thus in a 1950 application to the Rockefeller Foundation, Reed himself stated: "Counseling in human genetics is the modern way of carrying on a program in Eugenics . . . the term 'Eugenics' has fallen by the wayside and 'Counseling in Human Genetics' is taking its place."² And two years later, he wrote that, "it could be stated as a principle that the mentally sound will voluntarily carry out an eugenics program which is acceptable to society if counseling in genetics is available to them."³

Given the protean meanings of "eugenics," a plausible case can be made for each of his claims. In some respects, Reed seems decidedly anti-

eugenicist. Long before neutrality became fashionable, Reed argued that counselors ought not to impose their own values on their clients. The role of the counselor, he consistently argued, was "to explain thoroughly what the genetic situation is but the decision must be a personal one between the husband and wife, and theirs alone."⁴ Moreover, he wrote that the net effect of counseling might well be dysgenic. Reed often noted that the desire to compensate for the birth of an affected child was usually strong, while the recurrence risk was typically lower than the family had feared. Hence on balance, the effect of genetic counseling would be to encourage people to have more children than they otherwise would—thereby spreading the defective gene through offspring who were normal carriers.⁵ Reed's views on the appropriate stance for counselors and probable impact of their work hardly seem consistent with his characterization of counseling as the modern form of eugenics.

But Reed also believed that normal people could be relied on to make "rational" decisions—that is, to avoid bearing children at high risk for seriously abnormal conditions. Thus the impact of counseling could be described as eugenic even if its aim were relief of individual suffering rather than changes in the distribution of births and its means—provision of information to those who asked for it—were wholly voluntary. Second, while counseling might increase the incidence of particular disease genes, Reed and most of his peers assumed both that mental traits were more important than physical ones and that individuals who availed themselves of counseling services were generally impressive in intelligence and character. Therefore, counseling could be considered dysgenic in respect to disease and eugenic in respect to behavior. Third, any impact on the incidence of disease genes would be felt only in the distant future, with the immediate consequence being a reduction in the birth of affected children. Whether counseling appears to be dysgenic or eugenic is thus also a function of whether concern focuses primarily on long- or short-term effects. Depending on which factors are emphasized and how they are interpreted, counseling could be equated with eugenics—or with its antithesis.

That is why Reed could plausibly claim in the 1950s that counseling was a form of eugenics and with equal plausibility in the 1970s claim that it was not. But the question remains: Why would anyone want to identify counseling with such an ostensibly discredited enterprise? As we will see, "eugenics" in the 1950s still retained positive connotations for many scientists and their sponsors. Indeed, following Watson and Crick's 1953 discovery of the double-helical structure of DNA, it enjoyed a temporary resurgence in popularity. In the years immediately following the end of

World War II, the word "eugenics" virtually vanished from scientific journals. While arguments for selective breeding did not disappear, they were now mostly relegated to the conclusions of more general articles on eugenics or birth control.⁶ But publication of the Watson and Crick paper seems to have emboldened some geneticists. "Eugenics" began to reappear in the titles of articles in scientific journals. And as we will see, their arguments became more forceful and direct.

Thus there was little reason to avoid the association of eugenics with counseling. By the mid-1970s, however, "eugenics" had once again become a term of abuse. The shift in emotional resonance was accompanied by a contraction in the meaning of the word. Now that the association was damning, "eugenics" was typically restricted to compulsory programs. On the narrow definition, it was made unambiguously distinct from counseling.

This essay explores the ethos of medical genetics and genetic counseling as these fields developed in America and Britain in the two decades following World War II. In prior decades, some individual geneticists, such as Charles Davenport at Cold Spring Harbor and Lawrence Snyder and Madge Macklin at Ohio State University, had provided "marriage advice" to those who sought their help. Formal clinics had been established in Germany and Denmark during the 1930s. But in the Anglo-American world, genetic counseling was first institutionalized in the 1940s, when clinics were opened in Britain at the Hospital for Sick Children and in the United States at the Universities of Michigan and Minnesota. This essay asks: What were the aims of the field in the two decades following the end of World War II? How were sometimes disparate goals reconciled? How were these goals reflected in clinical practice? Are some of the tensions that once marked the field still manifest and, if so, in what ways?

Establishing Medical Genetics: Scientists and Their Sponsors

The Dight Institute was founded in 1941 with the explicit aim of promoting eugenics.⁷ A passage from the second annual Dight lecture exemplifies its ethos in the institute's early years:

In a commendable exhibition of sympathy and generosity, the nonproductive classes of society are being cared for on a plane of living which our productive members cannot afford for themselves. Very little is being done to protect our social system by our procedure in respect to

these dysgenic classes. The burden has already become so great that a surprising amount of our public expenditures in so-called normal times goes for the care of these nonproductive classes.⁸

The eugenic orientation reflected the aims of Charles Fremont Dight, a Minneapolis physician who left his estate to the University of Minnesota "to promote biological race betterment." Dight's many causes included birth control, socialism, and eugenics. A president of the Minnesota Eugenics Society, member of the Minnesota Birth-Control League, unsuccessful congressional candidate of the Public Ownership Party (1906), and socialist alderman for Minneapolis's 12th ward (1914 to 1918), Dight lobbied for a state sterilization law and, after its passage in 1925, for its extension to the noninstitutionalized.⁹ The equally eccentric Charles M. Goethe, a bank president and founder of the playground movement, also left much of his estate to what was by then the Dight Institute for its eugenic work, while the reactionary textile magnate "Colonel" Wycliffe C. Draper supported the Department of Medical Genetics at the Bowman-Gray School of Medicine in Winston-Salem, North Carolina (the first Department of medical genetics at an American university) and its director, C. Nash Herndon.¹⁰

With the exception of the U.S. Public Health Service, which funded cancer-related projects, virtually all institutional patrons of work in medical genetics and genetic counseling also had eugenic motivations. These included the Rockefeller, Carnegie, Wenner-Grenn, McGregor, and Rackham foundations, the Commonwealth and Pioneer Funds (the last founded by Draper in 1937), and the American Eugenics Society.¹¹

Across a wide political spectrum, scientists with an interest in medical genetics agreed that the field should serve to improve the race. To many scientists, it seemed self-evident that reproduction was properly a social and not just a private matter. Thus Ashley Montagu asserted in 1959 that, "there can be no question that infantile amaurotic family idiocy is a disorder that no one has a right to visit upon a small infant. Persons carrying this gene, if they marry, should never have children, and should, if they desire children, adopt them."¹² Linus Pauling, who believed that genetic defects were a primary source of human misery, proposed in 1968 that all young people be tested for the presence of the sickle-cell and other deleterious genes and a symbol be tattooed on the foreheads of those found to be carriers.¹³ In his 1970 presidential address to the American Association for the Advancement of Science, Bentley Glass speculated on the changes that would be prompted by exponential population growth. He wrote: "In a world where each pair must be limited, on the average, to

two offspring and no more, the right that must become paramount is not the right to procreate, but rather the right of each child to be born with a sound physical and mental constitution, based on a sound genotype. No parents will in that future time have a right to burden society with a malformed or a mentally incompetent child.¹⁴

Through the 1960s, most of the leading figures in medical genetics—including Oliver, Curt Stern, Lee R. Dice, Herluf Strandkov, Gordon Allen, William Allen, C. Nash Herndon, Franz Kallmann, Harold Falls, Madge Macklin and C. Clarke Fraser in the United States and Canada, Eliot Slater and Cedric Carter in Britain, and Tage Kemp in Denmark—bluntly described their work as a form of “eugenics.” The links between medical genetics and eugenics are nicely illustrated by the early history of the American Society of Human Genetics (ASHG), which was founded in 1948. Four of the first five Presidents—Dice, Snyder, Oliver, and Kallmann—were members of the Board of the American Eugenics Society. (Herndon also served as President of the ASHG in 1955, Reed in 1956, Stern in 1957, and Macklin in 1958.)

The exception was H. J. Muller. An ardent critic of “mainline” eugenics, Muller argued that eugenics in capitalist societies was hopelessly distorted by class and racial bias. But he was not opposed to eugenics per se. His 1949 presidential address to the American Society of Human Genetics, published as “Our Load of Mutations,” argued that identifying individuals carrying more than their share of the genetic load and convincing them not to reproduce was a matter of urgent necessity. But he consciously avoided using the word “eugenics” to describe his scheme. In Muller’s view, eugenic goals were best pursued under another rubric.¹⁵ Thus Muller differed from his peers in his view of appropriate tactics, not ultimate goals. He would certainly have agreed with Lee R. Dice, the first director of the University of Michigan’s Heredity Clinic, that “the heredity of the population should be of at least as much concern to each commonwealth as infectious diseases.”¹⁶ Summarizing a 1952 panel discussion on genetic counseling, Dice asserted: “We must give due concern to the possibility of eliminating, or, perhaps, of perpetuating, undesirable or desirable genes. We must not only be concerned with the particular family concerned, but also with whether or not harmful heredity may be continued or spread in our population.”¹⁷ That this was the prevailing view explains why the practice of genetic counseling was usually directive, and sometimes strongly so.

In the 1950s, genetic services came to be centered in major medical centers and physicians, who are trained to be directive, assumed a

greater role. A common view—that the attitude of neutrality “originated with counselors who were not engaged in patient care and who may have felt some reluctance, therefore, to enter into the lives of their counselees in the way a practicing doctor frequently does”—may thus seem plausible.¹⁸ But most of the research-oriented Ph.D. geneticists felt a similar responsibility to guide their clients. The views of Reed’s predecessor, C. P. Oliver, were typical: “A geneticist should prevail upon some persons to have at least their share of children as well as show a black picture to those with the potentiality of producing children with undesirable traits.”¹⁹

While the early postwar literature on counseling is replete with assertions that reproductive decisions belong to parents, they do not necessarily imply support for a neutral stance. Thus Oliver declared that parents should make their own decisions after they have been given all the facts. But physicians would also “make the picture as dark as possible” to help particular parents reach the conclusion that it would be best not to have more children.²⁰

Some clinicians expressed optimism that, advised of their hereditary defect, clients would generally follow their doctor’s advice. But most thought they needed at least a gentle push. Thus C. Nash Herndon, one of the two original staff members of the Heredity Clinic and first director of the Department of Medical Genetics at Bowman Gray School of Medicine, thought that “the counselor should attempt to encourage the marriage of persons of average or superior physical or mental capabilities, and should encourage such persons to have families. On the other hand, those with obvious hereditary defects . . . should be discouraged.”²¹ Franz Kallmann similarly believed that “persons requesting genetic advice cannot always be presumed to be capable of making a realistic decision as to the choice of a mate, or the advisability of parenthood, without support in the form of directive guidance and encouragement.”²² In his popular textbook, Curt Stern even anticipated the day when:

Natural selection will be superseded by socially decreed selection. In the course of time . . . the control by man of his own biological evolution will become imperative, since the power which knowledge of human genetics will place in man’s hands cannot but lead to action. Such evolutionary controls will be world wide in scope, since, by its nature, the evolution of man transcends the concept of unrestricted national sovereignty.²³

Distinguishing Good Eugenics from Bad

On conventional accounts, eugenics was wounded by the Depression and died with revelations of Nazi atrocities following World War II. Word and concept are said to have fallen into disrepute. But this generalization is much too broad. It is true that much of the public soon came to equate eugenics with the policies of the Third Reich. It is also true that the 1950s witnessed developments in medical genetics—broadly defined—that had little if any connection to eugenics. Research on the “inborn errors of metabolism” first identified by Sir Archibald Garrod at the turn of the century is particularly important, for it showed that some genetic diseases could be treated—a crucial step in the expansion of genetic services in the 1960s.²⁴

The idea that a genetic disease might be treatable was first suggested to a broad audience by Lionel Penrose in his 1946 inaugural lecture as professor of eugenics and head of the Galton Laboratory at University College, London. In “Phenylketonuria: A Problem in Eugenics,” Penrose stressed the complex causes of mental deficiency and argued that eugenic measures could have only a slight impact on its incidence. He also suggested that phenylketonuria (or PKU), although a genetic disease, might one day be ameliorated through an environmental intervention.²⁵

That day was in fact not far off. The severe mental retardation and other symptoms associated with PKU result from an excess of blood phenylalanine. (Due to a defective liver enzyme, phenylketonuric individuals are unable to catalyze the conversion of the essential amino acid phenylalanine to another amino acid, tyrosine.) In the mid-1950s, a number of groups began experimental treatment of phenylketonuric infants and children with low-phenylalanine diets. While their efforts initially met with only mixed success, the prospect of treating a genetic disease generated great excitement among public health officials, parents’ groups, and the press.²⁶ In an influential 1958 report commissioned by the National Association of Retarded Children, the neurologist Richard Masland wrote: “The fact that a disease is hereditary does not indicate that there is no form of therapy conceivable or that sterilization or other eugenic practices are the only hopes for modification of the problem. The modification of the stressful features of our environment, in the broadest sense of the word, may be an entirely proper and effective means of dealing with many genetic disorders.”²⁷

Two years later, a cheap and simple blood test, suitable for mass screening, became available. Within a decade, newborn screening for PKU and other inborn errors had become routine in the United States, Britain,

and much of Europe. These programs were defended in cost-benefit terms. Although all the metabolic disorders were rare, screening advocates successfully argued that the cost to the state of lifetime institutionalization for untreated individuals greatly exceeded the cost of the screening programs and diet required by affected infants and children.

Thus a competing model for medical genetics had already emerged in late 1950s. While preserving the orientation toward public health, and its associated cost-benefit language, newborn screening problems focused on treatment, not on selective breeding. (Most researchers in the area of human metabolic disorders were physicians and biochemists rather than geneticists.) At the same time, work in human cytogenetics was rapidly expanding. Joe-Hin Tjio, Albert Levan, Charles Ford, Paul Polani, Murray Barr, and Jerome Lejune, among others, greatly refined the analysis of chromosomes and thus laid the scientific groundwork for prenatal diagnosis.²⁸ Like the metabolic researchers, the cytogeneticists were generally uninterested in eugenics. Thus medical genetics had already begun to fragment as younger scientists with different interests entered the field.

At the same time, many geneticists whose professional careers began before World War II worried that eugenics’ rational core would be abandoned in the reaction to past abuses. Some even thought that a program of artificial selection was made more urgent by postwar military and medical uses of radiation, which they assumed were increasing the human mutation rate. Throughout the 1940s, 1950s, and even the 1960s, few geneticists objected to the characterization of applied medical genetics as “eugenics.” (Lionel Penrose, who insisted that his position as Professor of Eugenics be retitled Professor of Human Genetics, is a major exception.) For example, Lawrence Snyder noted that the practical applications of a knowledge of genetics include “the setting up of eugenic programs for the protection and improvement of society.”²⁹ In an article on X-linked mental retardation, William Allan, C. Nash Herndon, and Florence Dudley wrote that “when a sufficient body of data has been assembled to permit us to predict with accuracy the probably occurrence of mentally deficient children, we believe that a program of negative eugenics will do much to reduce the supply of disastrous children from these causes.”³⁰ In the 1950s and early 1960s, leading figures in the field routinely defined medical genetics as a worthy form of eugenics.³¹

Thus older geneticists generally continued to speak the language of eugenics, condemning past abuses but also taking for granted that reproduction was an act with social consequences and was thus legitimately a matter of social concern. The eugenics of the past, they conceded, was distorted by racial and class prejudice and simplistic scientific assump-

tions. But they insisted that eugenics has a rational core, which should be preserved. Some genes are unreservedly bad. Those that produce Tay-Sachs disease, muscular dystrophy, Huntington's Chorea, and other serious conditions bring only misery to their bearers and unnecessary expense to society. The struggle to eliminate disease genes must be sharply demarcated from past policies that targeted ethnic and religious minorities and the poor.³²

That was also the position adopted by the American Eugenics Society. Under the leadership of Frederick Osborn, distinguished scientists such as Theodosius Dobzhansky and Tracy Sonneborn were recruited to its board of directors. Osborn also increasingly turned the society's efforts toward the apparently neutral fields of birth control and human genetics. In 1954, the first issue of its new journal announced a series on "heredity counseling." During the next four years, an article on this theme appeared in almost every issue. In fact, between 1954 and 1958, the journal published more articles on counseling than on any other topic. The contributors constituted a virtual "who's who" in the field, most stressing its eugenic potential.

Public aversion to anything labeled eugenics ultimately swamped the "reform eugenics" movement. The society's general membership declined steeply. In a concession to public sentiment, its journal *The Eugenics Quarterly* was renamed *Social Biology* in 1968. Although some geneticists continued to employ the label into the 1970s, it was by then generally recognized that a successful eugenics program must be called something else. Commenting on the new title, Osborn remarked that "birth control and abortion are turning out to be great eugenic advances of our time. If they had been advanced for eugenic reasons it would have retarded or stopped their acceptance."³³ Or as he wrote in a popular 1968 book: "Eugenic goals are most likely to be attained under a name other than eugenics."³⁴

The commitment to birth control is not surprising. In the 1910s and 1920s eugenicists had divided on the question of its value. Some feared that the widespread practice of contraception "would prejudice the production of sufficient babies by the competent and far-seeing section of the community."³⁵ Others argued that the fittest members of society already limited their births and that the extension of contraception would therefore improve the race. Over time, as the futility of preventing its spread among middle- and upper-class women became increasingly evident, many eugenicists converted to the birth-control cause.

Furthermore, changing public opinion had left eugenicists with few other options. Coercive programs were no longer in vogue. Birth-control

advocates argued that, at least in respect to the normal population, there was no need for compulsion. The race would be improved by the voluntary actions of poor women who wanted to limit their births. The American Eugenics Society began aggressively to promote contraception. In 1952, Osborn was appointed the first director of the Population Council, an organization funded by John D. Rockefeller III to promote what was now often called "family planning."

But what could genetic counseling actually offer eugenicists? The answer is: very little. Those who turned to geneticists for advice (typically parents who already had a child affected with a genetic disorder or who were anxious about transmitting a trait that ran in the family) were confronted with a stark choice based on often vague estimates of risk. Until abortion was legalized in the United States by the 1973 Supreme Court decision in *Roe v. Wade* and in Britain by a 1967 Act of Parliament, the only legal way to avoid genetic risk was not to reproduce. But the right to terminate a pregnancy would have had little impact in the absence of practical methods for detecting genetic disorders during pregnancy. In the 1960s the first such method—amniocentesis—was developed, and by the mid-1970s it had become a routine part of clinical practice. The convergence of prenatal diagnosis and legalized abortion produced explosive growth in the field of genetic counseling. But in the three decades following World War II, it was practiced on too small a scale to make an appreciable difference in the population frequencies of the diseases in question. Thus from a eugenic standpoint, counseling was insignificant. Moreover, its impact was as likely to increase as reduce the incidence of particular disease genes (which is why Reed thought that genetic counseling might well be dysgenic).

The society's embrace of genetic counseling in part reflects its limited options in the postwar period. It also reflects the fact that eugenicists have in fact rarely focused on long-term effects. With few exceptions, such as Muller, the "gene pool" has been a distant abstraction. Eugenicists' have typically emphasized immediate impacts. Whether motivated by a desire to prevent suffering or to diminish the financial burden on society—or both—the focus has been on reducing the supply of "disastrous children" in the near term.

That eugenicists have always been more concerned with mental than physical traits also helps explain the indifference to potential dysgenic effects of counseling. Much early work on the heredity of clinical diseases was pursued by eugenicists who were at least as interested in behavior as health. Charles Davenport, for example, worked simultaneously on the inheritance of Huntington's Chorea, epilepsy, a cheerful tempera-

ment, and "nomadism." The 1931 edition of the influential textbook *Human Heredity* by Erwin Baur, Eugen Fischer, and Fritz Lenz describes hundreds of anomalies and normal traits, some of which are today considered hereditary and some not. Like all human genetics textbooks in the 1930s and 1940s, it discussed diseases, socially aberrant behaviors, and a host of mental and temperamental characteristics. Its catalogue of traits included glaucoma, various cancers, Parkinson's disease, susceptibilities to rickets, hypertension, and gallstones, as well as schizophrenia, manic-depressive insanity, homosexuality, idiocy, genius, power of imagination, and talents for painting, technical invention, and science.

Most geneticists would have agreed with Lenz that "the mental differences among men are not only much greater than the physical, but also far more meaningful."³⁶ In Germany, the physically handicapped were subjected to sterilization and, later, murder. But even there, eugenicists emphasized mentality and behavior. Most sterilizations carried out under the 1933 Law for the Prevention of Progeny with Hereditary Diseases law were for feeble-mindedness, schizophrenia, and alcoholism. Only about one-tenth were for physical disorders.³⁷

The interest in behavior carried over into the postwar period. For example, the principal projects of the Dight Institute in 1952 included mental deficiency and "normal intelligence and differential fertility" along with more obviously medical studies. Even after the American Eugenics Society began to support work in medical genetics, mentality remained its primary concern. Osborn thought that the eugenics movement should not emphasize physical health. What really matters is a change in reproductive behavior by the intellectual elite.³⁸ Physical improvement will follow from any program concerned with mental qualities, which are in any case much more important. "Eugenics is particularly interested in the psychological traits of intelligence and personality, because these traits are of major importance to civilization," he explained. "If there is justification for a broad eugenics movement, it is chiefly because of the part played by heredity in providing the necessary potentials for the development of high qualities of intelligence and personality."³⁹

The trait valued above all others was intelligence. In Muller's view, "For man, it is world of mental life which counts by far the most, the rest being pretty much subsidiary," while Neel claimed that, "given that the most important and precious asset of any human being is his intelligence, the impact of a convincing demonstration of this on national priorities would surely exceed the conquest of a dozen rare genetic diseases."⁴⁰

Most clinicians believed that it was the total genotype, not the single gene, that mattered. Thus Herndon argued that "one must not only con-

sider the obvious abnormality which prompts the patient to seek genetic advice; one must also take into account all evidence that may be obtainable concerning the total genetic potential of the parties concerned."⁴¹ Concerning a case where the wife had surgery for a harelip and cleft palate, he concluded that the couple's intellect and general genetic endowment were "sufficiently above normal that their reproduction might be advantageous to society as a whole, offsetting the disadvantage of the possible continuation of the defective gene."⁴² Dice likewise believed that "the obligations of a heredity clinic will not be fully discharged . . . if it confines itself entirely to the heredity of medical pathologies." Thus in giving advice, the geneticist should take into account "mental ability, and social worth in addition to hereditary defects."⁴³ According to Madge Macklin, "In dealing with these patients who ask advice, one must consider not only the fact that they have inherited diseases which they may transmit, but also whether they have highly desirable characters which they may pass on."⁴⁴

The belief that those who availed themselves of counseling were superior in mentality and character to the general population illuminates some objections to directive counseling. Reed believed that "the counselor has never suffered the particular circumstances which the parents of the affected child suffered and therefore cannot completely understand their feelings."⁴⁵ He also assumed that individuals motivated to consult a counselor were usually well above average in character and intellect. Thus behavior that is dysgenic with respect to a particular defective gene might still be desirable since, "those people who are sufficiently concerned about their future children to come to the Dight Institute for counseling have commendable concepts of their obligations as parents and these laudable characteristics should be transmitted to the next generation."⁴⁶ Harold Falls argued that the fact that they seek genetic advice indicates that the prospective parents are more intelligent and socially and morally responsible than most and reasoned that they "should actually be encouraged to have children (anticipating transmission of superior qualities) providing the gene to be transmitted does not impose too serious a handicap on the affected child."⁴⁷

Clinicians who opposed directiveness also assumed that their clients did not need guidance to make the right choice. "From my experience in giving advice about heredity to families in all walks of life I can affirm that every parent desires his children to be free from serious handicap," wrote Dice. "If there is known to be a high probability of transmitting a serious defect, it would be an abnormal person indeed who would not refrain from having children."⁴⁸ Thus counseling would automatically serve

the interests of both individuals and society. Given adequate information, the type of middle-class people who availed themselves of genetic services would act rationally. Neel consistently condemned eugenics and opposed directive counseling; he also argued that we should use all ethical means to limit the number of those unfortunates incapable of fully participating in our complex society. In his view, genetic counseling represented one such means, "since once the principle of parental choice of a normal child is established, it seems probable that in large measure the parental desire for normal children can be relied on to result in the purely voluntary elimination of affected fetuses."⁴⁹ Cedric Carter likewise noted that most parents and patients act sensibly on the basis of the counselor's advice.⁵⁰ Or as Reed remarked, "People of normal mentality, who thoroughly understand the genetics of their problems, will behave in the way that seems correct to society as a whole."⁵¹

Irrational individuals were a different matter. Writing of problems in counseling individuals with phenylketonuria, Reed argued that "no couple has the right to produce a child with a 100 per cent chance of having P.K.U., and it is doubtful whether a couple has the right deliberately to take a 50 per cent chance of producing such a serious defect."⁵² (Since the fitness of the recessive homozygote is nearly zero, there would be no effect on the "gene pool.") Thus the case against directive counseling was based on the assumption that most families would act responsibly, not on a principle of procreative liberty.

The New Ethos of Genetic Services

Two decades later, counseling services in the United States and Canada began a rapid expansion. The first master's level program for professional counselors, at Sarah Lawrence College, was established only in 1969. At that time, about eighty percent of counselors were physicians, while another eleven percent were Ph.D. geneticists.⁵³ While few of these counselors admitted to giving outright advice, most thought that it appropriate to inform their clients in such a way as to guide them to an appropriate decision. In 1973, F. Clarke Fraser noted that, over time, he had "evolved in a more rather than less directive approach in giving genetic advice."⁵⁴ But forces were quickly building in the opposite direction.

Primary among these was the transformation in public attitudes toward reproductive responsibility that took place in the 1960s and 1970s. No longer was it assumed that society had a legitimate interest in who reproduced. Within genetic counseling, concern for the future of the

population was replaced by concern for the welfare of individual families, as defined by the families themselves. That change reflected events specific to the field as well as general trends in the culture. Master's-level genetic counseling developed largely outside the field of medical genetics. Thus none of the founders of the first program at Sarah Lawrence were geneticists.⁵⁵ In other ways as well, the new counselors were different from their predecessors. All but a handful were women, who generally value reproductive autonomy more than do men.⁵⁶ They were also trained in "client-centered" therapy, which stresses the counselor's role in clarifying the client's own feelings.

In a classic 1972 article, Claire Leonard, Gary Chase, and Barton Childs asserted that "genetic counseling is preventive medicine and should be so regarded."⁵⁷ By the end of the decade, few counselors would agree. They had rejected not just eugenics but also the public-health orientation that informed the world of researchers on human metabolic disorders. These counselors rarely spoke the language of cost-benefit analysis, much less of selective breeding. They did not aim either to spare future generations' suffering or to save the state money. Instead, they hoped to empower their clients to make their own decisions according to their own values.⁵⁸ "Individual choice" and "personal autonomy" became the new catchwords. Of course theory and practice may sometimes—or even often—diverge. But at least in North America, the shift in ethos was dramatic.

Genetic services are now everywhere justified as increasing the choices available to women. In its 1983 report, the President's Commission for the Study of Ethical Problems in Medicine and Biomedical Research identified the primary value of screening for cystic fibrosis (CF), the most common recessive genetic disease among Caucasians of European descent, as providing people with the information they would consider helpful in autonomous decision-making—an aim reiterated in a 1992 report of the Office of Technology Assessment (OTA).⁵⁹ On the new view, counselors aim to serve only their clients, never society. The Professional Code of Ethics of the National Society of Genetic Counselors defines the counselor-client relationship as "based on values of care and respect for the client's autonomy, individuality, welfare, and freedom."⁶⁰ This view is likewise reflected in the 1994 recommendations of the Institute of Medicine's Committee on Assessing Genetic Risks. "The standard of care should be to support the client in making voluntary informed decisions" to the committee. *The goal of reducing the incidence of genetic conditions is not acceptable, since this aim is explicitly eugenic; professionals should not present any reproductive decision as 'correct' or advantageous for a person or society.*⁶¹

But at the level at which public policy is made, genetic services were and are still funded in hopes of reducing the incidence of genetic disease and thus saving the state money. In the 1970s, the U.S. government played a major role in promoting amniocentesis. Theodore Cooper, then assistant secretary of the Department of Health, Education, and Welfare, wrote at the time: "By focusing on prevention we increase the resources available for other programs. Few advances compare with the resources in their capability for prevention of disability."⁶²

Given the current bitter debate over abortion, it is unlikely that he would speak so openly today. A recent government report on health-care objectives illustrates how reticent officials have become. It proposes the goal of increasing to at least ninety percent the proportion of women enrolled in prenatal care who are offered prenatal screening and counseling for fetal abnormalities. The authors explain that "in the event of a fetal abnormality, testing and counseling early in the pregnancy provides an opportunity for families to prepare for a disabled infant, and increasingly, for medical interventions to correct some problem in utero." Abortion is never mentioned. Indeed, cross-pressures from the anti-abortion movement have produced schizophrenic policies in some states. For example, Tennessee forbids the use of public funds for prenatal diagnosis of conditions for which there is no effective therapy on the grounds that abortion is against public policy—while also legislating that public funds may be used for abortion in the case of fetuses with "severe physical deformities or abnormalities, or severe mental retardation."⁶³ But while cost-saving is often at war with other motivations, and today is rarely made explicit, it remains an important aim of genetic services programs. As the philosopher Arthur Caplan has noted, "When the state of California offers [a test] to all pregnant women it does so in the hope that some of those who are found to have children with neural tube defects will choose not to bring them to term; thereby, preventing the state from having to bear the burden of their care."⁶⁴ Economic appraisals of prenatal screening programs generally assume that benefits arise only from abortion of an affected fetus.⁶⁵

As in the past, many presume that these individual and social interests are congruent—that families will act "rationally." Thus policy analyses of screening programs typically presume that all identified fetuses will be aborted.⁶⁶ Today, everyone favors increasing the choices available to women. But fostering reproductive autonomy is rarely, if ever, the primary goal of governments when they choose to fund genetic services.⁶⁷ That states expect to save money is evident in the arguments actually made to legislatures, which are typically framed in cost-benefit terms.

Thus it seems that the new consensus on reproductive autonomy rests on the old assumption that families will ordinarily make the "right" decisions.

That assumption is questionable. As Rayna Rapp has noted, "There is no inevitable bridge between a positive diagnosis and an abortion."⁶⁸ The women she interviewed did not necessarily, or even generally, equate testing with abortion. Under hypothetical circumstances, most people are receptive to the idea of being screened. But many of those who express positive attitudes toward prenatal testing indicate that they would not abort even if the test identified a serious genetic condition.⁶⁹

That finding is confirmed by studies of attitudes toward pregnancy termination for specific disorders. In general, they show a reluctance to abort for medical conditions except where certain early death or severe mental retardation is involved. For example, while most women are interested in knowing their CF carrier status, they are hesitant to use that information to prevent the birth of an affected child.⁷⁰ Thus only twenty percent of parents of children with CF say they would abort an affected fetus—a higher percentage than for many other conditions, such as an incurable, severe, painful disorder that strikes at age forty.⁷¹ Of three hundred women participating in a program of MSAFP screening for neural tube defects, seventy-one said they would refuse abortion "even if the fetus had multiple, severe handicaps such as hemiplagia and bowel and bladder incontinence."⁷² Although ninety-seven percent of individuals at high risk for autosomal dominant polycystic kidney disease (a late-onset disorder that results in renal failure), and fifty percent would use prenatal testing, only eight percent would terminate a pregnancy for that reason.⁷³ Of course people may behave differently when facing an actual choice than they say they would when presented with a hypothetical scenario. But the proportion of women choosing abortion is often much lower than predicted on the basis of attitude surveys.⁷⁴ The actual reluctance of women to terminate pregnancies for fetal conditions helps explain the low utilization rates for some DNA-based tests.

Many eugenicists thought that the job of ridding the world of the "unfit" could be as easily—or even better—carried out by individuals themselves. They only needed to be educated and given the tools for the job. But even women who are not opposed to abortion per se are often uneasy with selective abortion. Willingness to abort for fetal conditions is associated with class and ethnicity: nonwhites, and the less wealthy and educated, are more tolerant of handicaps.⁷⁵ Their resistance to selective abortion has exposed stresses that were muted when genetic counseling was a small-scale enterprise, clients were overwhelmingly white, educated, and

middle class, and prenatal diagnosis was unavailable. With the expansion and increasing diversity of the client population, it is becoming evident that reproductive choice and "public health" models of genetic services do not easily cohere.

As genetic tests become cheaper and more reliable, and as they become increasingly applicable to common diseases (representing large markets), incentives will mount to screen more women for more disorders at an earlier age. The 1992 OTA report on the implications of CF carrier screening noted: "Without offering judgment on its appropriateness or inappropriateness, OTA finds that the matter of CF carrier screening in the United States is one of when, not if."⁷⁶ As screening programs expand, counseling is increasingly provided by obstetricians who do not fully share the professional counselors' commitment to principles of autonomous decision-making and informed consent and fear becoming targets of malpractice or wrongful-birth suits if they fail to test.⁷⁷ Thus screening tests are increasingly framed as a routine part of medical care.⁷⁸ Indeed, the strongest variable in determining uptake of screening is not the attitudes of consumers but the approach taken by the health-care provider; high usage is achieved by active recruitment.⁷⁹ The contradictions between autonomy and public health models is thus intensifying. How they are resolved—or suppressed—will reveal whether the contemporary consensus on reproductive autonomy is apparent or real.

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Notes

1. Sheldon Reed, "A Short History of Genetic Counseling," *Dight Institute Bulletin*, no. 14 (1974), 4-5.
2. "Proposal," *Rockefeller Archive Center*, North Tarrytown, N.Y.; Record Group 1.1, Series 200, Box 154, Folder 1393. I am grateful for the Division of Research Programs of the National Endowment for the Humanities for its research support. Special thanks are due Sheldon Reed for allowing me access to his papers and to Peter Coventry, Sharon Dufry, and Robert Resta for insightful comments on earlier drafts of this essay.
3. Sheldon Reed, "Hereditary Counseling and Research," *Eugenical News* 37 (1952): 43.
4. Sheldon Reed, *Counseling in Medical Genetics* (Philadelphia, 1955), 14.
5. *Ibid.*, 4-15.
6. Susan Johnson, "Eugenics in the Aftermath of WWII: A Study of Articles in *Science, Nature*, and the *Scientific Monthly*," paper, History of Eugenics seminar, University of Massachusetts/Boston, 1995.
7. Clarence P. Oliver, "A Report on the Organization and Aims of the Dight Institute," *Dight Institute Bulletin*, no. 1 (1943), 2.
8. Elmer Roberts, "Biology and Social Problems," *Dight Institute Bulletin*, no. 4, 18.
9. Phelps, "The Eugenics Crusade of Charles Fremont Dight," *Minnesota History* 49

(1984): 99-108; Sheldon Reed, "A Short History," 1-3; E. Swanson, "Biographical Sketch of Charles Fremont Dight," *Dight Institute Bulletin*, no. 1 (1943), 9-22.

10. For standard accounts of the founding of Bowman-Gray, see Ian Porter, "Evolution of Genetic Counseling in America," in H. A. Lubs and F. de la Cruz, eds., *Genetic Counseling* (New York, 1977), 26, and Marston Meads, *The Miracle at Hawthorne* (Winston-Salem: Medical Center of Bowman-Gray School of Medicine and North Carolina Baptist Hospital, 1988), 51, where Draper is characterized as "a New York philanthropist with a deep interest in population genetics." Draper wished to fund individuals and institutions with the proper attitudes toward "(a) miscegenation, (b) immigration quotas, (c) improving population quality by (1) positive, (2) negative measures." Ruggles Gates to Sheldon Reed, August 13, 1954.

11. On the Pioneer Fund, see Barry Mehler, "The New Eugenics: Academic Racism in the U.S. Today," *Science for the People* 15 (May/June 1983): 18-23, and essays by Adam Miller, "Professors of Hate," and J. Sedgwick, "Inside the Pioneer Fund," in R. Jacoby and N. Glauberman, eds., *The Bell Curve Debate: History, Documents, Opinions* (New York, 1994), 162-78, 144-61. On the Rockefeller Foundation, see Diane B. Paul, "The Rockefeller Foundation and the Origins of Behavior Genetics," in K. Benson et al., eds., *The Expansion of American Biology* (New Brunswick, N.J., 1991), 262-83.

12. Ashley Montagu, *Human Heredity* (New York, 1959), 305-6.

13. Linus Pauling, "Reflections on the New Biology," *UCLA Law Review* 15 (1968): 267-72.

14. Bentley Glass, "Science: Endless Horizons or Golden Age?" *Science* 17 (1971): 28.

15. H. J. Muller, "Our Load of Mutations," *American Journal of Human Genetics* 2 (1950): 111-76; see also Diane B. Paul, "Our Load of Mutations' Revisited," *Journal of the History of Biology* 20 (1987): 321-35.

16. Lee R. Dice, "The Structure of Heredity Counseling Services," *Eugenics Quarterly* 5 (1958): 40.

17. Lee R. Dice, "Concluding Remarks," in "A Panel Discussion: Genetic Counseling," *American Journal of Human Genetics* 4 (1952): 346.

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26. Diane B. Paul and Paul J. Edelson, "The Struggle over Screening," in D. de Chadarevian and H. Kammings, eds., *Molecularising Biology and Medicine: New Practices and Alliances, 1930s-1970s* (Reading, England, forthcoming).

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28. On developments in human cytogenetics, see Kevles, *In the Name of Eugenics*, 238-68.
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 33. Frederick Osborn, Transcript, Oral History Interview (July 10, 1974), Columbia University, New York, 7.
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 38. Frederick Osborn, "Editorial," *Eugenics Quarterly* 1 (1954): 2.
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 40. Muller, "Our Load of Mutations," 165; James V. Neel, "On Emphases in Human Genetics," *Genetics* 78 (1974): 39.
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 52. Sheldon Reed, *Parenthood and Heredity* (New York, 1964), 85.
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77. *Ibid.*, 151-52. There are currently only about one thousand Master's-level counselors in the United States.

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JAMES HARVEY YOUNG

Health Fraud: A Hardy Perennial

Quackery forms a gaudy thread in the fabric of health care through the course of American history. In the colonial years, the American market for commercial self-dosage was dominated by "patent medicines"—some of them actually patented—shipped overseas from the mother country.¹ Packed in containers of distinctive shape, sealed in wrappers printed with boastful therapeutic claims, advertised in the slender newborn press, these British nostrums far overshadowed occasional American imitators.

The Revolution ended this monopoly, and cultural nationalism generated an outpouring of made-in-America nostrums promoted in advertising that flaunted the flag and the eagle. The nascent industry kept expanding aided by cultural democracy linked to the political democracy associated with Andrew Jackson's name. Common schooling made the nation's citizens literate enough to read the lurid advertising in the county weeklies of the west and the penny press of eastern cities. Nostrum makers, pushed by competition, became brash and braggart, pioneering the ingenious ramifications of the psychology of advertising.

In the post-Civil War Gilded Age, the nostrum boom soared to new heights. Wood-pulp paper expanded the press enormously, and magazine advertising truly took hold. As of 1900, patent medicines led all product categories in the amount of money spent for national advertising. Chromolithography created colored trade cards. "The advertising quack," observed a physician in the 1880s, "is the black wolf, aye, the Bengal tiger of the profession. . . . He is full of shrewdness and cunning, and knows poor, weak human nature like a book."²

The charlatan's ads often sought to induce sickness in the healthy reader by translating mild transitory conditions such as low spirits, mild insomnia, or spots before the eyes into harbingers of insanity and syphilis. Scar-