Science in Context **11**, 3–4 (1998), pp. 481–491

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Genetic Services, Economics, and Eugenics

The Argument

What are the aims of genetic services? Do any of these aims deserve to be labeled "eugenics"? Answers to these strenuously debated questions depend not just on the facts about genetic testing and screening but also on what is understood by "eugenics," a term with multiple and contested meanings. This paper explores the impact of efforts to label genetic services "eugenics" and argues that attempts to protect against the charge have seriously distorted discussion about their purpose(s). Following Ruth Chadwick, I argue that the existence of genetic services presupposes that genetic disease is undesirable and that means should be offered to reduce it. I further argue that the economic cost of such disease is one reason why governments and health care providers deem such services worthwhile. The important question is not whether such cost considerations constitute "eugenics," but whether they foster practices that are undesirable and, if so, what to do about them. The wielding of the term "eugenics" as a weapon in a war over the expansion of genetic services, conjoined with efforts to dissociate such services from the abortion controversy, has produced a rhetoric about the aims of these services that is increasingly divorced from reality. Candor about these aims is a sine qua non of any useful debate over the legitimacy of the methods used to advance them.

Introduction

What are the actual aims of reproductive genetic services? Why are tests offered by health care providers, funded by governments, and reimbursed by insurers? Is the aim to increase the choices available to women, or to prevent birth defects, or both? Is preventing birth defects a legitimate goal? Is it acceptable if motivated by the desire to prevent suffering? What if the motivation is (or is also) cost-saving? Do one or more of these aims constitute "eugenics"?

In most circles, "eugenics" remains a term of opprobrium. There are exceptions. A number of scholars have recently argued that some form of eugenics may be defensible (e.g. Harris 1992; Maddox 1994; Kitcher 1996; Robertson 1996). In the literature of cyberspace, parents' freedom to choose the genotypes of their offspring — a private, "decentralized, do-it-yourself eugenics" — is even celebrated (e.g.

Morton 1998). But the participants in most debates on genetics-related issues, and certainly the bioethicists who serve on government commissions and professional society committees that pronounce on these issues, assume that eugenics of any kind is objectionable. To label a policy that aims at preventing birth defects "eugenics" is thus to condemn it. For example, the authors of a recent Institute of Medicine report assert that "the goal of reducing the incidence of genetic conditions is not acceptable, since this aim is explicitly eugenics" (Andrews et al. 1994, 14–15). The eugenics charge is leveled even more often at statements that assume that the cost of genetic disease is one reason to try to reduce its incidence, and in particular at the use of cost-benefit analysis to measure the success of genetic services. In response to the eugenics charge, many clinicians, researchers, policy analysts, and bioethicists claim that the aim of genetic services is (or should be) something other than preventing birth defects, and especially that their cost is not (or should not be) a consideration in deciding whether to provide or expand a service or in evaluating its success.

Meanings of Eugenics

While claims that particular policies constitute eugenics rarely illuminate the nature of the policies, they do illustrate how varied are the meanings and confused the uses of the term. For example, it has been charged that all cost-benefit reasoning in the reproductive realm is eugenics since "we are effectively changing the gene frequency by lowering the number of offspring with 'defective' genes" (Karjala 1992, 160). This charge rests on the false assumption that reproductive practices that are efficient from a cost-benefit standpoint will necessarily reduce the incidence of disease-causing genes. Prenatal diagnosis followed by selective abortion, or carrier detection resulting in avoidance of genetically-risky matings, will prevent the births of children with particular defects. That will at least sometimes save money for health-care providers. But these strategies will not reduce the incidence of the responsible genes, and under some conditions, use of prenatal diagnosis may increase it.[1]

Other confusions arise from the fact that the boundaries between what is and what is not considered eugenics are both contested and constantly shifting (see Paul 1992, 1997). As the above discussion indicates, eugenics is sometimes identified with efforts to improve the gene pool. However, when the *Dor Yeshorim* program, which permits matchmakers in Hasidic Jewish communities to avoid marriages between carriers for Tay-Sachs disease, is characterized as a "eugenic

[1] Selective abortion may increase the frequency of deleterious alleles for the following reason: Prior to the advent of prenatal diagnosis and legalization of abortion, the birth of a child with a disabling genetic condition often led parents to forgo further reproduction. The children themselves rarely if ever reproduced. Now parents who selectively abort have normal fertility, and some proportion of their children will be heterozygote carriers.

solution to a culturally perceived problem" (Marfatia, Punales-Morejon, and Rapp 1990, 116), the authors implicitly reject this definition. (It is interesting to note that, in an earlier day, "masking" strategies, such as that employed by the Hasidim, were seen as the antithesis of eugenics.) The line dividing eugenics from something else has been drawn in a myriad of other ways as well. For example, eugenics has been equated with a focus on behavior, as opposed to clinical disease, as in C. Keith Boone's assertion that "there is a seismic moral difference between treating leukemia and enhancing IQ," and that to move from the one to the other involves a "leap from therapeutic to eugenic measures" (Boone 1988, 11). Eugenics has often been identified with coercion, either narrowly or broadly defined. In the former case, it is equated with state-enforced measures, such as programs to segregate or sterilize the "feebleminded"; in the latter, with pressures arising from social and economic circumstances, such as the cultural prejudices and financial costs faced by parents of children with disabilities. It is also sometimes conversely associated with practices freely chosen or even demanded by individuals (so-called "back-door" or "private" or "homemade" or "do-it-yourself" eugenics [e.g. Duster 1990]). That expansive approach would be endorsed by Abby Lippman, for whom all prenatal diagnosis is *ipso facto* eugenics. She writes that "biomedical authors almost unanimously reject any suggestion that [prenatal] testing may be eugenic" notwithstanding the fact that it constitutes "an assembly-line approach to the products of conception, separating out those products we wish to develop from those we wish to discontinue" (Lippman 1992, 144). "Eugenics" has been employed even more broadly, as a label for policies unrelated to genetics. For example, it has recently been applied to adoptions of immigrant Yemenite Jewish children by families of European Jewish descent, and to the segregation of the blood of Ethiopian Jews in Israeli blood banks (see Pfaff 1997, 23, and the critique by Falk 1998, 61). In these cases, the word functions to associate disfavored beliefs or practices with programs that have terrible associations. It is meant to arouse revulsion.

If "eugenics" is to retain any link to its historical meaning and practice, the beliefs, activities, or results so labeled must have some relation to selective breeding. Nor should definitions exclude people or practices or beliefs closely associated with the eugenics of the past. Thus, to equate eugenics with coercion (a favorite line of demarcation) is to exclude some of its best-known advocates, especially in Britain, where there was near-consensus that eugenic measures should be voluntary (see Paul 1995). While we can therefore judge some definitions as too broad and others too narrow, the history of eugenics is itself too complex and admits of too many readings to allow us to stipulate one definition. My aim in this paper is therefore not to explain what eugenics really is — an impossible task. It is rather to explore some unintended consequences of efforts to stigmatize particular policies with that label.

What Are Genetic Services For? Conflicting Perspectives

The rationales for genetic services are many and varied. According to one U.S. government report, they both permit treatment and allow parents to prepare for the birth of a child with disabilities. The authors of the report urge much greater utilization of prenatal diagnosis, explaining that "in the event of fetal abnormality, testing and counseling early in pregnancy provides an opportunity for families to prepare to care for a disabled infant, and increasingly, for medical interventions to correct some problems *in utero*" (*Healthy Children 2000* 1991, 152). Apparently, prenatal diagnosis has nothing to do with abortion (a topic not easily discussed in a U.S. government publication in the 1990s).

Genetic services are more often said to provide reassurance, on the grounds that most women will receive a negative result. Patricia Ward, a genetics counselor at Baylor College of Medicine, stresses the "immeasurable joy" in learning that one's unborn child is free of genetic disease (quoted in Bishop and Waldholz 1990, 269). An allied claim is that prenatal diagnosis allows high-risk couples, who might have refrained from reproduction, to have children.

An even more common claim is that genetic services exist to increase procreative liberty. David Morris notes that prenatal tests "are often justified on the grounds that they foster reproductive choice and individual autonomy," and he explains that such testing "encourages effective choice by augmenting the number of reproductive options available to individuals who are bearing or who have considered bearing children. By increasing the amount of information available during pregnancy, prenatal diagnosis provides individuals the opportunity to make more informed choices regarding childbirth" (Morris 1994, 300). On this (widespread) view, the content of those choices is of no concern to providers or the state.

Others assume that genetic services aim to reduce the incidence of birth defects. But as to why this is a worthy goal, there is little agreement. Many stress the value of genetic tests in alleviating human suffering. The suffering in question is usually identified as that of the children-to-be, and the illustrations are often horrific: Lesch-Nyhan or Tay-Sachs disease or Hurler syndrome, conditions where affected children live short lives filled with pain (see Kitcher 1996).[2] Less often, the aim of reducing the financial and emotional burden on families is cited. Only rarely is there explicit acknowledgment of the potential reduction in costs to insurers or the state.

However, many critics of screening programs believe this rationale to be primary. In their view, claims that genetic services are offered to allow for treatment,

[2] For the child-to-be, the alternative to living with a genetic disease is not to be born at all. Thus according to one philosophical line of argument (deriving primarily from the work of Derek Parfit [1976; 1984]), the argument from the suffering of the particular child is specious except in those rare cases where living with a particular disease represents a worse fate than non-existence. Invoking horrific diseases avoids this problem (although it would not satisfy David Heyd [1992], who believes there are insuperable problems in comparing life to non-existence). For a recent critique of the metaphysical arguments about genetics and harm to children, see Green (1997).

prevent suffering, provide reassurance, increase procreative choice, or allow parents to prepare for the birth of children with disabilities, are simply disingenuous. They note that there are few effective interventions in the course of genetic disease. As Ruth Schwartz Cowan (who is not a critic) observes: "We need to be very clear about what therapy is currently available for most diseases or disabilities that can be diagnosed prenatally: *none* (Cowan 1992, 246).

The claim that relief of suffering motivates provision of genetic services is usually dismissed on the grounds that the suffering is an artifact of society's failure to make sufficient provision for individual with disabilities and/or that its degree is greatly exaggerated. (It is notable that whereas advocates tend to cite devastating diseases, critics tend to cite conditions that are mild, or even cosmetic). The claim that genetic services provide reassurance is countered with the claim that, on the contrary, it is the process of testing that arouses the anxieties that the results are then said to alleviate. The claim that genetic services are intended to increase procreative liberty is likewise dismissed as hollow rhetoric. According to critics, the real motivations are exposed when geneticists take their shoes off, so to speak. According to Ruth Hubbard and Eljah Wald: "Genetic researchers often justify requests for funding by stressing the economic costs of caring for disabled babies. Such eugenic concerns frequently hover in the background of statements scientists, physicians, and genetic counselors make, even when they claim only to be interested in the individuals who manifest a genetic condition or who believe their offspring to be at risk for one" (Hubbard and Wald 1993, 27).

What Are Genetic Services For? Realities

It is beyond the scope of this paper to sort out all of these competing claims. But I think we can say with the critics that the primary aim of genetic services is to reduce birth defects — not to increase the reproductive choices available to women, or provide reassurance, or permit treatment, or allow families to prepare for the birth of children with disabilities. International survey research confirms that "'prevention of birth defects' is a major goal of genetics in most nations" (Wertz 1997, 334). As Arno Motulsky notes, "when the government provides funds for genetic services, such support is obtained under the premise that genetic disease will be prevented." He goes on to ask whether freedom of reproductive choice can be reconciled with such a goal, suggesting that, "fortunately, most parents will in fact select a course of reproductive action that coincides with that thought appropriate by society" (Motulsky 1980, 239).

The authors of the Institute of Medicine report assert that reducing the incidence of genetic disease is unacceptable eugenics (Andrews et al. 1994, 14–15). In their view, reproductive genetic services should only "be aimed at increasing control over reproductive options" (Andrews et al. 1994, 8). But as Ruth Chadwick has persuasively argued, this is to confuse ends and means. "As a matter of logic," she

writes, "the goal of a medical genetics service must be connected in some way with the incidence of genetic disease. ... The very fact that geneticists think it desirable to offer their service to individuals shows that there is at least a presumption that it is undesirable to suffer from genetic disease and that means should be offered of avoiding it" (Chadwick 1993, 45). Indeed, this assumption is necessarily shared by those critics, such as Lippman, who argue that prenatal diagnosis is inherently eugenic. A commitment to reproductive autonomy is a *constraint* on the means used to achieve a reduction in birth defects, not an end in itself.

Hubbard and Wald are also right about the economic concerns that hover (or sometimes hover) in the background. One motivation for combating genetic disease is the hope of saving money by averting births of infants with costly disorders. That aim is evident in the writings of many health economists, policy-makers, and even medical geneticists (especially when they appeal to legislators for funds). During the 1970s, when such services were first established, and geneticists not so wary as they are today about speaking bluntly, it was common for geneticists to stress the financial cost of genetic disease. For example, Ronald Conley and Aubrey Milunksy wrote:

> In 1975 over 20,000 infants with chromosomal abnormalities will be born in the United States, and over 700,000 worldwide. The prodigious economic implications of such births provide cause for serious concern, especially with the advent of prevention through carrier detection and prenatal genetic diagnosis. ... Each year, with the birth of hundreds of thousands of chromosomally defective offspring, a future commitment to care by society in excess of two billion dollars is created. Over 20 years, without consideration of the costs of inflation, the commitment will have grown to about forty billion dollars. (Conley and Milunsky 1975, 442)

Conley and Milunksy also note that, "despite the importance of the emotional costs involved in the birth of retarded children, appeals for expanded preventive efforts are more readily received and acted upon when they are supported by firm benefit-cost and cost-effectiveness analyses" (ibid., 454).

Even today, scientists sometimes cite cost along with other considerations. Thus James Neel suggests that elective abortion is a necessary means not only to meet parental concerns for normal, healthy children but to reduce "the burden of chronic genetic disease on parents and society (which in most countries is assuming the costs of these genetic diseases)" (Neel 1994, 361; see also 368). John Maddox, past editor of *Nature*, similarly comments that, "many families will welcome the promise of not having to care for genetically handicapped children. Who can deny them that opportunity, especially when the societal costs of rearing and treating such children are considered?" (Maddox 1994). Cost considerations are often evident in statements by analysts and policy-makers who stress (without explicit mention of abortion) birth defects' price to society (e.g., California Birth Defects Monitoring Program; Waitzman, Romano, and Scheffler 1994). They are reflected

in the conventional practice of measuring the success of genetic counseling in terms of the number of pregnancies terminated. As a report of the Office of Technology Assessment notes, "in the values and language of cost-benefit analysis, prenatal genetic testing programs in which fewer than 50 percent of parents chose to terminate a fetus diagnosed with a genetic disorder are considered to be a 'failure'" (OTA 1992, 153). They also inform cost-benefit analyses of amniocentesis, where averted births typically count as the benefit to be weighed against the financial cost of testing (see Conley and Milunsky 1975; Hagard and Carter 1976; Hook 1979; Sadovnick and Baird 1981; Andreano and McCollum 1983; Conley 1985; Edel and Edel 1985; Crandall, Lebhertz, and Tabash 1986; Goldstein and Philip 1990; Haddow et al. 1994; Shackley 1996). A recent analysis of savings resulting from use of DNA diagnosis for cystic fibrosis, Duchenne muscular dystrophy, myotonic dystrophy, and fragile X syndrome convinced Dutch health officials to add what they call "genetic counseling" to the set of health care services provided under the public insurance system (van der Riet, van Hout, and Rutten 1997, 745).

I do not mean to imply that genetic counselors view success in such terms. At least in the U.S. and Canada, they rarely aim to save the state money. Counselors rather tend to view their role as helping clients make their own decisions, whatever their substance. But genetic services are funded by governments and insurers. To invoke counselors' attitudes as a rejoinder to the claim that cost-saving is a consideration in the provision of genetic services is to make a category mistake.

To equate such considerations with "eugenics" is to guarantee dissembling about motivations. Providers of course want to save money. And as Daniel Wikler notes, when funds are scarce, a good argument for any medical service — such as immunizations, prenatal care, or newborn screening programs for treatable metabolic disorders like PKU, none of which could be regarded as eugenic, is that they save more money than they cost (Wikler, forthcoming). It is notable that Hubbard and Wald themselves invoke cost-benefit considerations in opposing population-wide cystic fibrosis carrier screening. Following Benjamin Wilfond and Norman Fost, they comment that it would cost more than a million dollars for each child who might otherwise develop the condition (Hubbard and Wald 1993, 35).

Of course, there is a crucial difference between prenatal diagnosis and childhood immunizations. From a cost-benefit standpoint, the greater the number of abortions for some specific condition, the more efficient the genetic service. Hence cost-benefit analysis provides an incentive to expand services and maximize the rate of terminations of pregnancy for expensive disorders (Clarke 1990, 1146). Thus it may generate pressures in a sphere which many believe should remain private and personal. These pressures are likely to increase with increasing health care costs, the development of tests for more common conditions, and the expanding role of primary care physicians (who tend to be much more directive than are genetic counselors) in the delivery of genetic services (see Caplan 1993, 153–156). Claims that cost-benefit analysis in the reproductive sphere is "eugenics" often

signal anxiety about this trend. The use of such analysis is indeed in real tension with a commitment to patient autonomy. For that reason, cost-benefit analysis (at least of a standard sort) may be inappropriate in the reproductive sphere. But it does not follow that cost-benefit analysis *per se* is eugenics.

Conclusion

The existence of genetic services presumes that it is worth reducing the incidence of birth defects. One of those reasons, for at least some who support such services, is economic. The need to deny this, out of fear of being tagged with the eugenics label, has led to dissembling on a massive scale. In 1988, the authors of an OTA report on the Human Genome Project wrote in a famous/notorious passage that, "human mating that proceeds without the use of genetic data about the risks of transmitting diseases will produce greater mortality and medical costs than if carriers of potentially deleterious genes are alerted to their status and encouraged to mate with noncarriers or to use artificial insemination or other reproductive strategies" (OTA 1988, 84). That was perhaps the last time that public officials acknowledged, at least openly, that reproductive genetic services might save money. Given the outcry, their reticence is understandable (for example, see Annas 1989, 20, where the OTA passage is equated with Justice Holmes' defense of involuntary sterilization in the 1927 case of *Buck v. Bell* — in spite of the authors' condemnation of sterilization).

If we equate cost considerations with "eugenics," there will be no debate as to whether these are ever legitimate and, if so, under what circumstances, and how best to limit whatever undesirable pressures they may create. Here, as elsewhere, the charges of "eugenics" and resultant efforts to defend against those charges have served to divert attention from more substantive issues. The crucial question is not whether efforts to reduce the incidence of genetic disease, or cost-savings as a motive for these efforts, or cost-benefit analysis as a tool in these efforts constitute eugenics. The important question is what we want from genetic services, and what means we should — and should not — employ in pursuit of those ends.

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Wikler, D., forthcoming. In *In the Shadow of Eugenics* (tentative title), edited by A. E. Buchanan, D. Brock, N. Daniels, and D. Wikler.

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