

CHAPTER 5

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FROM REPRODUCTIVE RESPONSIBILITY TO
REPRODUCTIVE AUTONOMY

1. INTRODUCTION

That procreation is a basic human right, with which the state has no business meddling, is today the dominant view among Western genetics professionals, bioethicists, and journalists. In their perspective, reproductive genetic services should aim at increasing the choices available to women. Since no reproductive choice is right or wrong, clinicians should be scrupulously neutral in their dealings with clients. Any other approach constitutes "eugenics."

This perspective is encapsulated in a passage from an Institute of Medicine report: "The goal of reducing the incidence of genetic conditions is not acceptable, since this aim is explicitly eugenic; professionals should not present any reproductive decisions as 'correct' or advantageous for a person or society" (Andrews, 1994, p. 15). The authors take for granted that eugenics is bad, an assumption nearly universally shared by geneticists in North America and much of Europe (which is not to say that they agree on what eugenics is). Assessing geneticists' responses to questions in two large, international surveys, Dorothy Wertz writes: "The word *eugenics* almost never appeared in North American or European reasoning, except as an example of unspeakable evil, having been totally discredited by the Nazi's actions" (Wertz, 1998, p. 156).

Yet, earlier in the century (as well as in many countries today), the view that reproduction is entirely a private matter was anything but obvious. Indeed, in the 1910s, 1920s, and 1930s, the opposite view was generally taken for granted even by critics of the eugenics movement of their day (see Paul and Spencer, 1995). Although there was opposition to eugenic sterilization, it did not necessarily imply

opposition to eugenics *tout court*, much less to the view that reproduction was a matter of social concern. It was generally assumed that mentally deficient individuals should be prevented from breeding. The issue was how best to achieve this end. Sterilization was sometimes criticized as ineffective, or based on unfounded assumptions about the heredity of mental defect, or inevitably biased in its application (e.g., see Davies, 1930, pp. 94-120). A paramount concern was that it would provide a cheap substitute for the more desirable policies of segregation, training, and community supervision. But such criticism of means should not be confused with the claim that procreative liberty is a right.

The Catholic Church was the most influential opponent of sterilization. In his famous 1930 papal encyclical *Casati Connubi* ("On Christian Marriage"), Pope Pius XI criticized those who, "over-solicitous for the cause of eugenics" propose to interfere with "the natural right of man to enter matrimony" (Pius XI, 1931, p. 31). He particularly condemned sterilization as an illegitimate arrogation by the state of power over the bodies of its subjects. In the absence of a crime, he argued, public authorities have no business physically harming their subjects. But the Catholic position on reproduction did not reflect a pro-autonomy perspective. Indeed, immediately after criticizing this use of state power, the Pope noted that private individuals are also barred from tampering with their bodies in order to "render themselves unfit for their natural functions" (p. 33). That the Church hardly considered procreation a private matter is indicated by the condemnation, in the same encyclical, of contraception and abortion.

Nor was the Church unremittably hostile to eugenics. In the 1931 encyclical, Pius XI conceded that eugenics must "be accepted, provided lawful and upright methods are employed within the proper limits" (p. 31; see also Lepicard, 1998). According to his successor, these included efforts to dissuade (though not forbid) carriers of grave genetic disorders from marrying each other, and use of the rhythm method to prevent conception where married couples risk transmitting a severe disease. While reiterating the ban on sterilization and other means of birth-control, he wrote: "Better warned of the problems posed by genetics and of the gravity of certain hereditary diseases, men of today have, more than in the past, the duty to take account of this increased knowledge so that they might forestall countless physical and moral difficulties for themselves and others" (Pius XII, 1959, p. 13). In the 1950s and 1960s, distinguished Protestant theologians, as well as many progressively-minded geneticists, also argued that individuals at high risk of transmitting a serious genetic disease should refrain from reproducing. Some of them maintained that if individuals failed to discharge their reproductive responsibilities, the state should intervene.

Views common in the United States through the 1960s now horrify when they are expressed by officials in China, where a law explicitly titled "On Eugenics and Health Protection" was proposed in 1993. The government did not anticipate the furor that the law prompted in the West. The 18th International Congress of Genetics, held in Beijing in August 1998, was officially boycotted by the national genetics societies of England, Holland, and Argentina, and shunned as well by

numerous individual scientists (Rosenthal, 1998, p. 14). Moreover, many geneticists who attended the Congress did so on the condition that there would be opportunities to criticize the by then renamed Maternal and Infant Health Care Law.

Because it included provisions permitting doctors to sterilize individuals with serious genetic conditions without their consent, the law was said to contravene article 16 of the United Nations Universal Declaration of Human Rights, which states that "men and women of full age, without any limitation due to race, nationality or religion, have the right to marry and to found a family," and to violate basic norms governing the provision of genetic services. In response, the Chinese government eliminated the references to "inferior births," and, following the 1998 Congress, it officially suspended the offensive provisions. According to the new policy, sterilization would be allowed only with the consent of the couple or a guardian (Pomfret, 1998, p. 10). Of course, the degree to which practice changed, if at all, is another question.

From the reaction to the Chinese law, it would seem that views in the West have been transformed. Today, many people are shocked by assumptions the rightness of which their grandparents took for granted. One aim of this chapter is to explain how and why this apparent sea change in attitudes occurred. Another is to question its depth and breadth, for it appears that the public is less committed to the principle of respect for reproductive autonomy than are those "who are authorized to speak for and defend" that public in bioethical matters.¹

2. WHAT HAPPENED TO EUGENICS?

The worldwide economic depression undermined the identification of status with genetic worth. For that reason, it is often assumed that enthusiasm for eugenics—and with it, the view that the state has a legitimate interest in who reproduces—waned in the 1930s. However, the Depression also increased pressures to sterilize individuals who would otherwise require expensive institutionalization. Thus, in 1935 George Reid Andrews could remark on the "rapid and remarkable" progress of eugenics, and note that people "who a few years ago were indifferent if not hostile to the teachings of eugenics, are now deeply interested because of the practical bearing of these teachings upon the problems of the present depression" (1935, p. 1). During the 1930s, when support for eugenics is said to have eroded, sterilization laws were passed in Germany, the Canadian provinces of Alberta and British Columbia, Norway, Denmark, Sweden, Finland, Iceland, and Estonia, while in the United States, the number of procedures performed under the older laws climbed (Paul, 1995, pp. 72-90). Japan passed a sterilization law in 1940 (Otsubo and Bartholomew, 1998).

In the immediate aftermath of World War II, eugenics did become unfashionable. Revelations of Nazi atrocities produced a general revision against genetic explanations of individual and group differences. The pendulum swung, at least briefly, from a hereditarian to an environmentalist perspective. As Dorothy Nelkin and Susan Lindee have noted, "nurture triumphed indisputably in both the

scientific and popular rhetoric of the 1950s and much of the 1960s. The stories of biological determinism that had characterized the eugenics literature were replaced by narratives of cultural determinism" (1995, p. 34). But they also note that this cultural shift was short-lived. A variety of factors, including anxieties over long-term genetic damage resulting from atmospheric nuclear testing, well-publicized advances in medical treatment, and a perceived population explosion, soon converged to produce renewed enthusiasm for the view that it would be socially irresponsible for some kinds of people to reproduce.

Even in the 1950s and 1960s, eugenic language persisted among professionals in fertility and in human genetics (Nelkin and Lindee, 1995, pp. 34-7; see also Kevles, 1985, pp. 251-68; Wright, 1994, pp. 23-6). Indeed, something of a backlash among geneticists was evident shortly after the war's end. Classical geneticists such as H. J. Muller and Julian Huxley, who had championed programs of selective breeding before the war, now renewed their campaigns. In his 1949 Presidential address to the newly founded American Society of Human Genetics, Muller argued that the human species was deteriorating under an ever-increasing load of deleterious mutations. In his view, this burden was attributable both to expanded military and medical uses of radiation (especially atmospheric nuclear testing), and to therapeutic advances in medicine, which allowed individuals who would once have died before childbearing to survive and reproduce. To counter the threat of degeneration, he proposed a scheme under which the most burdened three percent of the population would voluntarily refrain from reproducing (Muller, 1950; Paul, 1987). A few years later, he also resurrected a proposal of the 1930s to bank the sperm of men outstanding in regards to their intellect, temperament, character, and physical traits (a program now called "germinal choice" to emphasize its voluntary character).

Muller's warnings about genetic deterioration, and hopes of genetic improvement, appear to have resonated widely; echoes of his argument are found in numerous popular articles and scientific symposia. The spell he exerted is reflected in Tracey Sonneborn's comment that Muller's contribution to the 1963 symposium on The Control of Human Heredity and Evolution "was received with such enthusiasm by the audience that, after hurried consultation with some of the other speakers, we agreed it would be anticlimactic and quite undesirable to throw it open for general discussion" (1965, p. 124).

Interest in the control of human evolution, which is reflected in the many symposia in the 1960s on the genetic future of humankind, was also spurred by the discovery of the double-helical structure of DNA and unraveling of the genetic "code" (Ludmerer, 1972, p. 181). Molecular scientists such as Francis Crick, Joshua Lederberg, Salvador Luria, Linus Pauling, and Robert Sinshelmer began to debate the pros and cons of what Muller called "genetic surgery" and Rollin Hotchkiss (in 1965) termed "genetic engineering" (see Kay, 1993, pp. 275-6; Kevles, 1985, pp. 258-68; Wright, 1994, pp. 123-4). Some scientists, such as Luria, argued for caution. Others, perhaps emboldened by their achievements in manipulating life, urged intervention.

Muller's pessimistic view of the future, should a *laissez-faire* attitude prevail, was shared by many molecular scientists. Even Lederberg, who was generally skeptical of schemes to control human breeding, asserted that "the facts of human reproduction are all gloomy—the stratification of fecundity by economic status, the new environmental insults to our genes, the sheltering by humanitarian medicine of once-lethal defects" (Lederberg, 1963, p. 264). Crick went much further. At the famous 1962 CIBA Foundation symposium on Man and His Future, Crick expressed his agreement "with practically everything Muller said" about the urgent need both to prevent further genetic deterioration and to increase the proportion of superior genotypes in the population. In place of the current *laissez-faire* system of reproduction, Crick argued, we might substitute a licensing scheme, whereby "if the parents were genetically unfavorable, they might be allowed to have only one child, or possibly two under special circumstances" (Wolstenholme, 1963, p. 275). Commenting on Crick's suggestion, N.W. Pirie asserted that, on the question of whether there is a right to have children, "in a society in which the community is responsible for people's welfare—health, hospitals, unemployment insurance, etc.—the answer is 'No'" (Wolstenholme, 1963, p. 282).

Five years later, Pauling, who was also influenced by Muller, proposed that all young people should have tattooed on their forehead symbols for any seriously defective recessive genes, such as those producing sickle cell anemia and PKU. He expressed confidence that, if this were done, carriers for the same defective gene "would recognize the situation at first sight, and would refrain from falling in love with one another." He also thought that "legislation along this line, compulsory testing for defective genes before marriage, and some form of public or semi-public display of this possession, should be adopted" (Pauling, 1968, p. 527). Pauling was concerned that one long-term effect of such a program would be a slight increase in the future incidence of disease genes. But he thought that result could be countered through an educational process aimed at convincing carriers "married to normals" to have fewer than the average number of children. (It is notable that he explicitly characterized his scheme as a form of "negative eugenics.")

Muller's scientific assumptions and policy proposals were strenuously contested, but the view that reproduction is not simply a private matter was accepted even by some of his severest critics. Among Muller's most influential antagonists were geneticist Theodosius Dobzhansky and anthropologist Ashley Montagu. In a book that took issue with virtually every other aspect of Muller's eugenics, Dobzhansky remarked that persons who carry serious genetic defects should be persuaded not to reproduce, and if persuasion should fail, "their segregation or sterilization is justified" (1962, p. 333). He continued: "We need not accept a *Brave New World* to introduce this much of eugenics." Montagu likewise wrote that, "there can be no question that infantile amaurotic family idiocy [Tay Sachs disease] 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" (1959, pp. 305-6). Sheldon Reed, who coined the expression 'genetic counseling,' also asserted that no couple has the right to knowingly produce a child with a serious

genetic disorder (1964, p. 85). Montagu, Dobzhansky, and Reed, unlike Muller and Pauling, were unconcerned with the 'gene pool.' They thought the long-term would take care of itself. In their view, it was the potential short-term consequences, for the child-to-be and perhaps for the larger society, that mattered. But all the scientists agreed that reproduction was a social concern.

In theology as well, intense disagreements about the nature of the problem and the validity and utility of various eugenic solutions have obscured underlying agreement on fundamental issues. During the 1960s, Protestant thinking on bioethical matters was dominated by two theologians: liberal Episcopalian Joseph Fletcher and conservative Methodist Paul Ramsey (Jonsen, 1998, pp. 34-51). Ramsey was an influential critic of the nascent field of genetic engineering, and he sparred with both Fletcher and many scientists over the ethics of sperm banking, cloning, and other real or potential genetic manipulations. At the same time, he argued that the marriage licensing power of the state be used to prevent the transmission of grave diseases. "After all," he wrote, "it ought never to be believed that everyone has an unqualified right to have children, or that children are simply for one's own fruition... The freedom of parenthood is a freedom to good parentage, and not a license to produce seriously defective individuals to bear their own burdens" (Ramsey, 1970, pp. 98-9). Fletcher frequently made the same point in even stronger terms. Indeed, as late as 1980, he claimed that, "reproductive rights are not absolute and those who are at risk for passing on clearly identifiable, severely deleterious genes and debilitating genetic disease should not be allowed to exercise their reproductive prerogative" (Fletcher, 1980, p. 131). According to Fletcher, "testes and ovaries are communal by nature, and ethically regarded they should be rationally controlled in the social interest" (1980, p. 134).

As noted earlier, the resurgence of interest in eugenics (now focused primarily on clinical disease rather than mental defect) was fueled in part by anxieties over the potential long-term genetic damage resulting from atmospheric nuclear testing, an issue vigorously publicized by Muller, whose 1947 Nobel Prize for the discovery of the mutagenic properties of X-rays allowed him to speak with great authority. But it was also buttressed by well-publicized advances in medical treatment, especially insulin therapy for diabetes and dietary treatment for phenylketonuria (PKU).² In the mid-1960s, the first population-wide screening programs to identify newborns with PKU were established. It soon became clear that as a result of such screening and treatment, individuals who would ordinarily not have reproduced would enjoy normal fertility. Although PKU itself was rare, it was thought at the time that dietary treatment would soon be available for a large number of metabolic conditions and that, in general, the new science would result in many more treatments for genetic disease. But unless the germ line could be directly altered, such progress would come at a cost to the 'gene pool.'

Sir Peter Medawar, a severe critic of Muller, argued that the follies of many past and present eugenic proposals should not prevent us from recognizing "that rationally founded and humane procedures in the area of negative eugenics are possible..." (1977, p. 61). He warned of the inevitable economic implications of

advances in therapeutic medicine, noting that, "if diabetics are to be kept alive and restored by medical procedures to something approaching a state of normal health, as it is right that they should be, then whatever elements of their genetic make-up may have contributed to their diseased state will for that reason be disseminated more widely throughout the population," and he suggested that carriers of the recessive gene for PKU be discouraged from marrying each other (Medawar, 1977, pp. 58-9, 63-4).

Modern medicine was also held responsible for a population explosion. At numerous conferences and in many books and articles, it was argued that, if world population were not checked, it would be impossible to maintain a minimum standard of living (e.g., Ehrlich, 1968). Proposals to lower birth rates ranged from encouragement of voluntary family planning to schemes involving direct social controls (for a summary of suggestions, see Berelson, 1969). The sense of alarm surrounding the issue is reflected in economist Kenneth Boulding's proposed system of marketable licenses to have children. He explained:

Each girl on approaching maturity would be presented with a certificate which will entitle its owner to have, say, 2.2 children or whatever number would ensure a reproductive rate of one. The unit of these certificates might be the 'deci-child', and accumulation of ten of these units by purchase, inheritance, or gift would permit a woman in maturity to have one legal child. We would then set up a market in these units in which the rich and the philoprogenitive would purchase them from the poor, the nuns, the maiden aunts, and so on. (Boulding, 1964, p. 135)

(Boulding thought the plan would have the added advantage of reducing income inequality, since the rich would have more children, leaving them poorer, while the poor would have fewer children, leaving them richer.)

Boulding aimed to solve the population problem while preserving a maximum of individual choice. But coercive proposals were also common, justified both by the gravity of the situation and by the assumption that limiting population growth is a public good unachievable through an appeal to individual families (which have economic or emotional interests in having more children). The concept of a "tragedy of the commons"—situations in which individuals acting rationally will produce an outcome in which everyone is worse off—was popularized by Garrett Hardin, who argued that, "the only way we can preserve and nurture other and more precious freedoms is by relinquishing the freedom to breed, and that very soon" (1968, p. 1248).

It was but a short step to the conclusion that, if breeding must anyway be limited, the restrictions should be selective, particularly since the population control movement had deep roots in the pre-World War II eugenics establishment. Indeed, all the main organizations and individuals promoting population control in the 1950s and 1960s had earlier supported eugenics research and advocacy (see Gordon, 1990, pp. 386-97). It was only natural for them to ask why procreative liberty should not be limited for the purpose of improving the population if it could legitimately be limited for the purpose of reducing its growth. Vance Packard summarized a common argument of the day: "If you are going to try to control the quantity of the population, why not also control the quality?" (1977, p. 257). This argument has

strong echoes in contemporary China, where eugenics has been justified by the one-child population policy. Thus, Sun Dong-Sheng (1981) of the Jinan Army Institute writes: "Eugenics can also play a considerable role in controlling population growth. If a couple gives birth to a disabled or retarded child, they will invariably want to have a second child. As a result, the proportion of our population which is of poor quality increases as does the overall birth rate."

Bentley Glass's 1970 presidential address to the American Association for the Advancement of Science exemplifies the often-asserted link between the need to restrict how many and who should reproduce. According to Glass,

in an overpopulated world, it can no longer be affirmed that the right of the man and woman to reproduce as they see fit is inviolate. On the contrary, if my own additional child deprives someone else of the privilege of parenthood, I must voluntarily refrain, or be compelled to do so. 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 every child to be born with a sound physical and mental constitution, based on a sound genotype. No parents will in that future time have the right to burden society with a malformed or a mentally incompetent child, just as every child must have the right to full educational opportunity and a sound nutrition, so every child has the inalienable right to a sound heritage. (Glass, 1971, p. 28)

For these (and perhaps other) reasons, proposals to limit reproductive freedom were widely discussed during the 1960s. In 1966, a writer for *Harper's Magazine* reported on a proposal, discussed at a human genetics conference, to issue licenses to reproduce only to those whose genes received a passing grade, and commented that "eugenic proposals like this are commonplace at scientific meetings nowadays. After twenty years of ill repute, eugenics is again the subject of respectable scientific investigation" (Eisenberg, 1966, p. 53).

Of course, the morality and utility of the enterprise were also strenuously criticized, and there were important countercurrents. Proponents of schemes for selective breeding often complained that they were swimming against the tide, especially if they advocated compulsion. Indeed, oppositional forces were building and would soon swamp efforts to rehabilitate both the term 'eugenics' and any principle of reproductive responsibility. Already in 1967, thirty nations signed a UN statement to the effect that "the Universal Declaration of Human Rights describes the family as the natural and fundamental unit of society. It follows that any choice and decision with regard to the size of the family must irrevocably rest with the family itself, and cannot be made by anyone else." In the same year, Kingsley Davis (who served as President both of the American Sociological Society and the Population Association of America) complained that "in the sphere of reproduction, complete intellectual initiative is generally favored even by those liberal intellectuals who, in other spheres, most favor economic and social planning" (Davis, 1967, p. 737). But within some professional communities, including genetics, there was little fear of characterizing favored policies as 'eugenics.' And even geneticists such as Dobzhansky or Montagu, who would have rejected the 'eugenicist' label, assumed that it was wrong to knowingly transmit a serious genetic disease.

Given the number of discussions in scientific circles about the need for reproductive restraint, it is understandable that many commentators at the time thought they had spotted a trend. For example, Harvard historian Donald Fleming wrote: "What we may reasonably expect is a continually rising chorus by the biologists, moralists, and social philosophers of the next generation to the effect that nobody has a right to have children, and still less the right to determine on personal grounds how many" (1969, p. 69). Similarly, Paul Ramsey thought it could "safely be predicted that the future will see more rather than less discussion of proposals for genetic control" (1970, pp. 1-2).

As it turns out, their predictions proved utterly wrong. Within a decade, views that seemed to Fleming, Ramsey, and many others in the 1960s to have been in the ascendancy were decidedly out of fashion. It may seem astounding that assumptions could change so quickly. But as Cass Sunstein has argued, allegiance to social norms is often weaker than it seems. What he terms a "norm cascade" can result if people with an interest in changing attitudes can exploit that fact (Sunstein, 1997, p. 36). In the 1970s, there were groups committed to changing norms in respect to reproduction. And a variety of events, described in the next section, allowed them to prevail.

3. THE RISE OF AUTONOMY

The social turmoil that began in the 1960s was one such development, particularly the closely linked patients' rights and feminist movements, which themselves followed on the civil rights and anti-war campaigns. Doctors' authority was denounced as patriarchal. "Our Bodies, Ourselves," as the book title had it, along with "autonomy," "choice," and "self-determination," became movement slogans (Gordon, 1990, pp. 400-6). To early feminists, autonomy implied "control over our bodies, our labor and economic resources, our life decisions," and as such was viewed as central to the achievement of feminist political goals (Di Stefano, 1996, p. 95).

At the same time, reproductive genetic services began a period of rapid expansion. Prior to the 1970s, few individuals made use of the limited genetic counseling services then available. Most of those who did came from families with a history of some disorder or already had an affected child. All the counselor could offer was an (often imprecise) estimate of risk. Moreover, the clients' choices were severely limited since the risk could be avoided only by refraining from childbearing. Under these conditions, genetic counseling had little to offer, and it remained a small-scale affair, mostly practiced by Ph.D. geneticists and by physicians trained in genetics (Porter, 1977, p. 23; Sorenson and Culbert, 1974).

That situation changed in the 1970s when the development of prenatal diagnosis coincided with the legalization of abortion. Amniocentesis was first developed in the 1960s, and entered clinical practice in the 1970s. In Britain, abortion was legalized by an Act of Parliament in 1967, while in the United States, the Supreme Court prohibited states from unconditionally barring the procedure in the 1973 case of Roe

v. Wade. As a result of this convergence, the demand for genetic services, and hence counselors, exploded. The earliest professional degree program in genetic counseling, at Sarah Lawrence College, graduated its first class in 1971. Its students were trained in techniques of Rogertian therapy, according to which the role of professionals was to clarify the clients' own values, not impose their own. The education of these overwhelmingly female students also coincided with the rise of the autonomy-oriented feminist movement.

It is of particular importance that genetic services expanded in the context of impassioned controversy over the morality of abortion. That charged social context guaranteed that medical geneticists and genetic counselors would stress clients' freedom to make their own decisions. After all, these professionals did not want to be accused of fostering such a contentious practice as abortion. Given the paucity of treatments for genetic conditions, the accusation that prenatal diagnostic services promoted abortion had considerable force. Denying that there was any correct reproductive decision functioned to defuse this charge; hence the insistence that the goal of reproductive genetic services, or at least the only acceptable goal, is increasing the choices available to women.³ According to the official view, "autonomous decision making should be the goal in prenatal diagnosis and... health professionals, society, and the state [should] be neutral on the outcome of individual reproductive choices. Reproductive genetic services should be aimed at increasing individual control over reproductive options and should not be used to pursue eugenic goals" (Andrews *et al.*, 1994, p. 103).

At least one other development is germane to the apparent shift in ethos. In the 1970s, bioethics emerged as a distinct intellectual discipline, and its practitioners became the new arbiters on a wide range of ethical issues in medicine. Although autonomy was originally proposed as one of four equally important values in bioethics, it soon came to dominate beneficence, nonmaleficence, and justice (Jonsen, 1998, p. 335; Wolpe, 1998, p. 43). And the principle of respect for autonomy was interpreted as implying that a person "should be free to perform whatever action he wishes—even if it involves serious risk for the agent and even if others consider it to be foolish" (Beauchamp and Childress, 1979, pp. 56-9; quoted in Jonsen, 1998, p. 335). The reasons for the triumph of autonomy are complex and perhaps not fully understood (see Jonsen, 1998; Wolpe, 1998). It is certainly significant that bioethics developed in the context of a series of scandals involving experiments on human subjects, most notably the Thalidomide disaster of 1961 (when testimony revealed that drug companies provided doctors with samples of experimental drugs, with doctors then paid to collect data on their patients), Henry Beecher's 1966 exposé of risky experiments conducted on patients at distinguished medical institutions without their knowledge or consent, and the 1972 exposé of the syphilis experiments at Tuskegee (Faden, 1996, pp. 80, 97-103). These and other scandals undermined the assumption that physicians could be trusted to act in their patients' best interests and therefore strengthened the case for patient autonomy.⁴ Susan Wolf observes that "bioethics has embraced a liberal individualism with more vigor than it has embraced anything else. The bioethics revolution to establish

patients' and research subjects' rights has been an effort to unseat both traditional physician paternalism and a societal willingness to sacrifice the individual. The central tool has been the esteem of the individual as an end not a means and as someone entitled to self-rule or autonomy" (Wolf, 1996, p. 16).

Given its emergence in the 1970s, bioethics was inevitably affected by the other emergent social movements, including civil rights and feminism, and by the general cultural fracturing of the time. Albert Jonsen notes in his recent history of the field: "In a pluralistic society, where broad agreement on the content of morality seemed to be fading, a principle of autonomy, as the sole or primary moral principle, solved many a conundrum; one merely respects the wishes and choices of every person without passing judgment on further moral grounds" (1998, p. 335). (He goes on to note that "this shallowest meaning of respect for autonomy, unfortunately, seemed the most readily grasped.") That assessment is fundamentally shared by Paul Root Wolpe, who notes that the principle of autonomy (at least as understood in bioethics) is relatively easy to apply, unlike the principles of nonmaleficence, beneficence, or justice, each of which has more obviously contested meanings and implications. "Once we agree on the primary importance of letting the patient decide," he writes, "finding a way to apply ideas of autonomy in the clinical setting becomes a technical problem" (Wolpe, 1998, p. 46).

In any case, what matters for us is that the principle of respect for autonomy came to dominate bioethics at a time when bioethicists began to replace scientists as the primary spokespersons on social and ethical issues in genetics. During the 1950s and 1960s, most books on this theme were authored by distinguished scientists, such as Theodosius Dobzhansky, Ashley Montagu, Linus Pauling, H.J. Muller, L.C. Dunn, and Julian Huxley. It was scientists to whom journalists, foundations, and conference organizers typically turned for guidance on genetics-related ethical issues. For example, participants at the 1962 CIBA Foundation meeting on Man and His Future included such scientific notables as H.J. Muller, Julian Huxley, Joshua Lederberg, J.B.S. Haldane, Albert Szent-Gyorgyi, Francis Crick, Peter Medawar, Gregory Pincus, Carleton Coon, and N.W. Pirie; five of the twenty-seven participants were Nobel Prize winners (Jonsen, 1998, p. 15). Indeed, of the four major symposia on this theme held in the 1960s, nearly all the participants were scientists; the debates were primarily between geneticists who believed that genetic engineering of humans was premature and those who believed that its time had come. But by the 1970s, the discourse on issues in genetics was dominated by bioethicists.

Bioethics today includes an increasing number of scholars critical of the weight accorded autonomy (as is also true for feminism). Among the critics of an autonomy orientation are bioethicists who reject a *laissez-faire* approach to reproductive decision making. These scholars have argued that there is a responsibility not to reproduce if the parents are at high risk of transmitting a serious disease. In their view, although no one should prevent a woman or couple from reproducing and bearing a child with a debilitating condition, it may be irresponsible for them to do so, especially given the possibilities of contraception, adoption, and assisted

reproduction with preimplantation genetic selection. These bioethicists insist on a distinction between ethical and legal/policy issues. They believe that some acts that may be immoral should not, for other important reasons (such as conflicts with other important moral values, "slippery slope" dangers, or practical considerations), be legally prohibited (e.g., Steinbock and McClamrock, 1994; Purdy, 1995).⁵ They would agree with Thomas Murray's charge that we have an unfortunate "tendency to conflate judgments about what is morally right and wrong with judgments about what are wise and defensible public policies" (Murray, 1996, p. 97; see also pp. 108-12).

Thus, bioethicists do not speak in one voice. What had been an ideological near-consensus in the 1970s and 1980s has begun to fracture. (However, Renée Fox argues that bioethics is moving in the opposite direction, toward a more individualistic and "private-entitlement" perspective [1994, pp. 49-50]). Wherever bioethics may be headed, autonomy—especially in respect to reproduction—generally remains a trump value. Those who argue that there are social responsibilities in procreation are a minority, and have little public presence. So we need to ask: to what degree are the values of bioethicists representative of other professionals and of laypersons? Has there really been a wholesale transformation in attitudes toward reproduction or does the appearance of such a transformation result, at least in part, from the fact that a group largely committed to a new norm was authorized to speak for everyone?⁶

4. THE COMPLEXITY OF NORMS

While changes in ethos have certainly occurred, the question is how broad and deep those changes have been. In reporting on the controversy sparked by the decision to hold the 1998 genetics congress in Beijing, many commentators remarked on the existence of a gulf between the values of Asians, who are said to place a premium on the collective good (and therefore reject the concept of reproductive autonomy), and Westerners, who ostensibly take individual rights as fundamental (and therefore approve it). But this generalization is overly broad. First, the "West" is not a useful category. International surveys conducted by Wertz and colleagues demonstrate substantial national variability among European genetic professionals regarding such questions as whether it is fair to conceive a child with a serious genetic disorder or whether counseling should be non-directive. The locus of opinion in Spain is quite different from Britain. Moreover, even in the most autonomy-oriented countries, opinion is hardly unitary. Although few U.S. geneticists would restrict a woman's or couple's right to choose, twenty-six percent agree that "it is socially irresponsible knowingly to bring an infant with a serious genetic disorder into the world in an era of prenatal diagnosis" (Wertz, 1998, p. 501).

Second, we should not assume that Chinese culture is monolithic. It is certainly true that the perspective of Chinese geneticists diverges greatly from that of their counterparts in the United States and Britain. For example, whereas ninety-two percent of Chinese geneticists agree that people known to be carriers of a recessive

genetic disorder should not marry each other (primarily because their children would have a one-in-four chance of inheriting the disorder), the figure for geneticists in the United States and Britain is six percent and seven percent respectively (Mao, 1998, p. 699). According to a Chinese geneticist involved with the survey, "the Chinese culture is quite different, and things are focused on the good of society, not the good of the individual. It would shock people in the West, but my survey reflects cultural common sense" (quoted in Coughlan, 1998, p. 18). In introducing the new law, China's Minister of Public Health asserted that "the state of inferior-quality births has aroused grave concern in the whole society, and their latent effects have alarmed and worried the people in various circles....[T]he broad masses of the people demand that a eugenics law be enacted and effective measures be taken to reduce inferior-quality births as quickly as possible" (Anonymous, 1995, p. 699). But we should be wary of generalizing from the expressed views of geneticists or any other elites to those of "the people." While there is evidence that the Minister's statements reflect the views of China's urban elite, we know little about the opinions of rural or marginalized people. Moreover, surveys indicate that even in the coastal cities, a significant minority disagrees with the official view (Dikötter, 1998, pp. 170-2).

Recently, Chinese medical ethicist Jing-Bao Nie (1999) has argued that there exist both individualistic and communitarian strains in Chinese society and hence its medical ethics, and he protests the simplification involved in equating Chinese culture with its classical works, official ideologies, or the views of elite spokespersons. He notes that there is no one Chinese perspective on abortion, approaches to death and dying, or any other issue in medical ethics.

In support of his argument, Nie draws on Martha Nussbaum's critique of generalizations about non-Western cultures. According to Nussbaum, *no* real culture is unitary. She writes: "Real cultures are plural, not single;" "Real cultures contain argument, resistance, and contestation of norms;" "In real cultures, what most people think is likely to be different from what the most famous artists and intellectuals think;" "Real cultures have varied domains of thought and activity," which extend beyond philosophy, religion, and literature, and include daily life and the lives of rural as well as urban people (Nussbaum, 1997, pp. 127-8). Ironically, Nussbaum thinks that we would readily "see the defects in a monolithic portrayal of 'American values,'" and urges us to be equally critical of such characterizations of China or India (1997, p. 127). But discussions of the Chinese eugenics law are rife with expansive generalizations about Western values. And they are misguided, for all the reasons she gives.

Even applied to the United States, where the tradition of liberal individualism, and its associated autonomy-centered ethic, has been especially strong, the contrast with China is overdrawn. After all, signs of discontent with the individualistic liberal ethic are everywhere evident both in scholarship and in ordinary social and political life.

Revisionist historians have challenged the once-prevailing assumption that eighteenth-century Americans were classical liberals. In the classical liberal perspective, it is expected that individuals will disagree about the nature of the good

life. The state should therefore adopt a stance of neutrality on religious and moral matters. Its proper role is to provide a framework of rights within which individuals will strive to achieve their own self-chosen ends. The content of those ends is none of the government's business. People should generally be allowed to live their lives as they please (but see Dworkin, 1994; Greenstone, 1993; Bird, 1999).

However, most social and intellectual historians now agree that the fundamental ethos of that era was actually a secular republicanism, which stressed communal responsibilities, mutual obligations, and the value of active participation in the life of the polity. Indeed, Michael Sandel has noted that the individualist version of liberalism is actually a late arrival, having displaced the rival republican tradition only forty or fifty years ago (1996, p. 5). Barry Shain (1994), in a recent critique of the revisionists, argues that eighteenth-century attitudes were dominated by a narrow and constraining Protestant-inspired vision, deriving from the dogma of original sin, rather than being truly republican in the classical or Renaissance sense. Nevertheless, he agrees that a version of communalism, not liberalism, was the dominant spirit of the Revolutionary and Founding era.

The search for an alternative past reflects contemporary dissatisfaction with liberal individualism. That discontent became manifest in the 1970s, when liberals, and particularly the liberal university with its claims to intellectual and moral neutrality, came under attack from the Left student activists. Today, liberals are again on the defensive. Few politicians today apply the label to themselves; more often they try to attach it to their opponents. But now the most powerful contemporary challenge to liberalism comes from the religious Right. While promoting *laissez faire* in the economic realm, most conservatives reject autonomy elsewhere. Wishing to impose a moral orthodoxy, they advocate restricting access to abortion, allowing prayer in schools, banning assisted suicide, imposing harsher sentences for drug use, barring gays from serving in the military, and so forth. On the intellectual level, discontent is reflected in the critiques of liberalism by "communitarians" of various political stripes, including Charles Taylor, Amitai Etzioni, Jean Bethke Elshtain, Robert Putnam, Michael Sandel, and Alasdair MacIntyre (who would disavow the label). It is also reflected in contemporary feminism, which as Christine Di Stefano notes, is now marked by "a complex ambivalence toward autonomy" (1996, p. 95). The negative voices include many socialist feminists as well as feminist theorists of an "ethics of care," such as Carol Gilligan, Sarah Ruddick, Nel Noddings, Eva Kitay, and Joan Tronto. Whatever their other differences, these scholars agree that liberalism (at least in its dominant, individualist form) provides an impoverished account of persons and their relationship to community and state, and fosters anomic and selfish behavior. Feminists add that it obscures patriarchal oppression.

At the same time as these theorists challenge the philosophical adequacy of an autonomy-centered ethic, ethnographers deny that it captures the values of the poor and marginalized (see Jennings, 1998; Fox, 1994). For many poor women, in particular, such an ethic seems to have little appeal. Thus, Elizabeth Bussiere has shown how the mostly black and female rank-and-file of the National Welfare

Rights Organization lived within "a web of concrete responsibilities" that made them suspicious of the abstract and universalizing rhetoric employed by the organization's primarily white, middle-class leaders (1997, pp. 112-7). She argues that the latter's language of autonomy, individual rights, contract, and consent conflicted with the women's sense of the nature of the self and of the particular obligations of motherhood, a conflict that ultimately fragmented the movement and contributed to its decline.

Given the complexity of the American political tradition, we should not expect consensus on the view that reproductive decisions are wholly a private affair. Consider the diverse reactions to the case of Bree Walker-Lampley, a highly successful CBS television news anchor in Los Angeles. Walker-Lampley and her daughter have a heritable condition that results in the absence of digits in both hands and feet. In July 1992, when she was seven months pregnant with a second child, Jane Norris questioned the morality of Walker-Lampley's pregnancy on the radio talk show she hosts. Norris asked her listeners whether they thought it was fair to "pass along a genetically disfiguring disease to your child." She said that she asked herself whether she would make the same decision and concluded that, given the availability of adoption, surrogate parenting, and other options, "I have to say, I don't think I could do it" (Mathews, 1991). She also urged her listeners to say whether they would conceive a child knowing that the baby would have a fifty-fifty chance of inheriting Walker-Lampley's condition (Anonymous, 1991a).

Most callers were highly critical of Walker-Lampley, asserting that her decision was unfair both to the child and to society. Others argued that the pregnancy was none of Jane Norris's business. The incident was widely publicized, with nearly all the television, radio, and newspaper commentators expressing dismay at the views of Norris and the majority of her listeners. The assertion by one genetic counselor—that society has no right "butting its nose into people's [reproductive] lives"—is typical (Seligmann, 1991, p. 73; Hubbard and Wald, 1993, pp. 30-1). Walker-Lampley was honored with the 1992 National Courage Award (Baden, 1992). She and her husband, joined by about one hundred individuals and twenty-five disabled rights groups, filed a complaint before the FCC, asking it to examine whether the station's owner should be fined, reprimanded, or lose its license. Commenting on the (ultimately unsuccessful) complaint, the chairman of the Equal Employment Opportunity Commission argued that the station should not be disciplined for debating the issue but noted that he was "appalled and sickened" by aspects of the program (Anonymous, 1991b, p. 33). The show and its aftermath reveal the plurality of views on the ethics of reproductive decision making and suggest where some of the fault lines lie.

Walker-Lampley's condition was hardly disabling, and talk-show callers may be a highly unrepresentative group. However, there is evidence that, when it comes to the issue of transmitting a serious disease (genetic or otherwise), many Americans do not share the perspective of genetics professionals and bioethicists. For example, according to M. Gregg Bloche, physicians who counsel HIV-infected women about their reproductive options often advise them not to get pregnant, and if they are

pregnant, to abort (1996, p. 258). He concludes that, "at the clinical level, the counseling of reproductive abstinence has been widely recommended and is probably an established practice" (Bloche, 1996, p. 260). The physicians' perspective is apparently shared by many laypersons. Surveys conducted by Wertz and her colleagues indicate that, unlike geneticists, most physicians and members of the American public think it is unfair to the child, to siblings, and to society in general to knowingly run the risk of having a child with a serious genetic disease (1997a). Indeed, eighty-one percent of patients—as opposed to ten percent of geneticists—believed that people at high risk of transmitting a genetic disease should not have children unless they use prenatal diagnosis and selective abortion (1997b). If we had a more nuanced picture of American culture, those statistics would not seem so startling.

This essay began by asking how a viewpoint that was generally taken-for-granted until the 1940s, and still seriously espoused in the 1950s and 1960s, virtually vanished from public discourse in the mid-1970s. We can now see that discourse was transformed to a much greater degree than were underlying norms. The social movements of the 1960s certainly produced changes in values, but those changes were very uneven. Respect for autonomy became a trump principle for various social and intellectual elites, particularly genetics professionals (for whom it served to defuse the conflict over abortion) and bioethicists. Since these are the groups whose opinions on reproductive issues are sought by governments and the media, the view that childbearing decisions are no one's business but that of the parents seemed to be general. But appearances are deceiving. Concern for social responsibility in reproduction has been a central theme throughout the twentieth century. There is less than meets the eye in the apparent transition to and dominance of an autonomy orientation. Given the shallowness of allegiances to the new social norm, we should not be surprised if attitudes shift again.

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NOTES

1. Paul Rabinow (1998) uses the phrase in reference to French intellectuals' disquiet with recent developments in science and technology.
2. Writing of the 1960s Albert Jonsen notes that geneticists worried that the gene pool was becoming polluted because the early death of persons with certain genetic conditions was now preventable (1998, p. 14). In addition to antibiotics, insulin for diabetes and diet for phenylketonuria were frequently mentioned.
3. Ruth Chadwick (1993) has cogently argued that fostering reproductive choice is not an ineffectual rationale for providing genetic services, since their very existence presumes that genetic disease is undesirable. See also Paul, 1998.
4. However, recent research indicates that patients themselves generally place a low value on autonomy; see Schneider (1998, pp. 35-46).
5. Deborah Mathieu (1996) has made an analogous argument in respect to preventing other forms of prenatal harm, such as damage resulting from drug use by a pregnant woman.
6. For an analogous argument on bioethicists' stem-cell debate, see Wolpe and McGee (in press).

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