The Resistible Rise of Preventive Medicine

Deborah A. Stone, Brandeis University

Abstract. The politics of preventive health care have changed dramatically in the last fifteen years. In the late 1960s and early 1970s, prevention was the motherhood issue of health care reform. With only the slightest glimmer of controversy, vaccination, promotion of lifestyle changes, mass screening, and safety regulation all became widely accepted strategies for improving health and reducing medical expenditures. By the mid-1980s, the dark side of each strategy became visible. Vaccinations can cause serious and permanent injuries; lifestyle factors are being used to raise insurance premiums, to deny eligibility for disability insurance benefits, and to deny employment. Screening is similarly used to deny employment, and new technologies for prenatal screening have raised fears of stigma and selective abortion among racial, handicapped, and antiabortion groups. Occupational safety regulation is increasingly focused on excluding the "high-risk" individual from jobs. In the absence of social protections from these economic and social harms, citizens have used tort and civil rights litigation to resist preventive health measures.

Prevention has always had an ambiguous status in health care politics. It is at once the darling of health care reformers and the stepchild of health care professionals and politicians. Everyone is in favor of the idea of prevention—stopping disease and injury before they happen—but few want to stake a career on such an uncertain business or invest public funds in preventive measures.

Although this discrepancy between ideology and practical politics has been a historical constant in preventive health policy, there has been tremendous change in the politics of prevention since the early 1970s. The political coalitions are different. The rhetoric and substantive issues of prevention have changed. And the political strategies of those favoring and opposing preventive measures have shifted.

What I will call the "old politics" involved a liberal, "do-good" reform coalition of public health researchers, physicians, labor, and advocates of the poor and children which was aligned against business and industry and the bogey of public ignorance. The rhetoric was missionary: the purpose of prevention programs was to bring better health to the poor, the uneducated, and the untreated. Through better health would come better performance in schools, better job op-
opportunities, and even upward social mobility. All this was to happen through the classic techniques of prevention: immunization against contagious diseases, mass screening to detect diseases in early stages, public education about lifestyle habits and health, and reduction of occupational health and safety hazards.

If the old politics could be described as missionary, the new politics might well be described as a colonial uprising. The new political line-up often has labor, women's groups, parents' groups, advocates for women and children, and a new breed of "ethics watchers" pitted against medical researchers, public health advocates, and industry. The new rhetoric emphasizes the paternalism of prevention measures, the dangers of coercion in the name of better health, and the protection of individual rights. The resistance uses the strategies of civil rights politics: identifying groups as minorities or victims of discrimination and oppression, mobilizing around these identities, and pursuing political objectives through the courts.

This article traces the transformation from the old politics to the new politics by examining each of the four classic strategies of prevention—immunization, promotion of lifestyle changes, screening, and occupational safety. I also seek to map out the new politics in some detail and make some predictions about the directions of prevention politics and policy in the next two decades.

One aspect of change in prevention politics occurs throughout the four areas, so it deserves a brief mention here: the backlash against prevention as not being "worth the cost." Prevention has always been health reformers' version of a "free lunch." It has been touted by advocates as making economic sense because, so the theory goes, it is cheaper to prevent diseases or treat them early than to treat full-blown cases and sustain the associated economic losses.

Of course, any prevention program has its own costs. A program that detects and treats diseases among the poor is especially likely to generate costs that would otherwise have remained invisible, because poor people do not receive much treatment and what treatment they do get is often covered by charity arrangements rather than "real" dollars. Moreover, the availability of third-party payment stimulates utilization of services; physicians are more likely to prescribe further diagnostic tests and more expensive remedies under a program where these things are paid for. Thus, prevention usually turns out to be more expensive than anticipated. If the alleged savings ever came, they would not show up for a long time. In the cost-containment mania of the 1970s and 1980s, it is no surprise that prevention should be rejected as a false prophet of economy.¹

Immunization

In a well-known essay published in 1974, Lewis Thomas declared vaccines the most exemplary of what he called "high technology" in medicine. Vaccines were the pinnacle of modern medicine, most of which he saw as still stuck in "halfway technology." He concluded by saying, "If I were a policy-maker, in-
interested in saving money for health care over the long haul, I would regard it as an act of high prudence to give high priority to a lot of basic research in biologic science." But in 1986, discussing development of an AIDS vaccine, David Sencer, M.D., former director of the Centers for Disease Control, told a reporter, "It may be that the lab work will be the quickest part of developing a vaccine. . . . The sociological problems are going to be horrendous." In a similar vein, J. Michael McGinnis, head of the HHS Office of Disease Prevention and Health Promotion, believes that the problems of structuring appropriate clinical trials for a vaccine, finding a manufacturer, liability, indemnification, and victim compensation may well be far more difficult than the research problem of finding a vaccine. What happened in between 1974 and 1986 to entangle the quintessential technological "fix" in a web of political, sociological and legal problems?

The development of the Salk polio vaccine in the mid-1950s led to a wave of optimism about the possibilities of disease prevention through immunization. A polio vaccination campaign began in 1955, accompanied by the Poliomyelitis Assistance Act of 1955 (P.L. 84-377). Between 1961 and 1968, 20 states made polio immunization a requirement for school attendance; by 1976, 47 states required at least one type of immunization as a condition for school entry.

Meanwhile, high technology turned out to have its flaws. In rare cases (probably fewer than one in a million), the vaccine actually caused polio. Vaccine-induced polio could happen in three ways. First, the original Salk vaccine was made with killed (inactivated) virus cells. If all the cells were not killed, vaccine recipients would be inoculated with live virus, as happened when 207 people contracted polio from a vaccine manufactured by Cutter Laboratories. Second, the killed vaccine did not protect the recipient's intestinal tract against infection, so the virus could be passed to nonimmune persons—for example, it could be passed by mothers changing their babies' diapers. Third, the newer oral vaccine, based on attenuated live virus cells, had the advantage of providing intestinal immunity, but apparently caused paralytic polio in over 100 people between 1969 and 1982, a ratio calculated at about 1 per 11 million doses. (Since standard practice calls for three doses per person, the risk of any individual contracting polio from the vaccine is obviously higher.)

These anomalies, coupled with a general climate of expanding products liability, led to a number of successful suits against drug manufacturers. From the manufacturers' viewpoint, the most significant cases were Davis v. Wyeth Laboratories (1968) and Reyes v. Wyeth Laboratories (1974). These decisions held that although it is not negligent for a manufacturer to put a vaccine on the market with such a small risk/benefit ratio, the manufacturer does have a duty to warn the recipient of the dangers of an "unavoidably unsafe product." The lack of a warning that would enable a person to make a truly informed choice is tantamount to putting an "unreasonably dangerous product" on the market, and manufacturers could be held strictly liable for the damages.

The manufacturers were left in an awkward position. They claimed they had provided adequate information to the state medical societies and to physicians,
and they had relied on physicians to inform their patients of the dangers. But because of the government’s polio campaign, the vaccine was generally dispensed in mass clinics and immunization centers, where there was little (if any) individualized discussion between vaccinees and physicians. The manufacturers wondered how they could possibly provide adequate warnings to all vaccinees in such a distribution system.

Thus, when the Department of Health, Education and Welfare (HEW) in 1976 announced its intention to mount a mass immunization campaign against swine flu, both manufacturers and their insurers were wary. The insurers feared a huge number of claims for which they would have to pay the legal defense costs, even if the manufacturers ultimately won. They cancelled manufacturers’ liability coverage for the vaccine. Manufacturers, cancellation notices in hand, told HEW they would not produce swine flu vaccine without coverage or some form of indemnification. And having committed itself publicly to a mass immunization program, the Ford administration pushed Congress to appease the manufacturers. Under the Swine Flu Act, which was passed in two weeks from start to finish, the federal government assumed the duty to warn vaccinees of risks; injured victims were allowed to sue the government under the Federal Tort Claims Act; and manufacturers could not be sued for harms arising from the vaccine unless they were negligent in producing the vaccine.

Since the swine flu affair, the politics of immunization have changed irreversibly. First, there is a greater public consciousness of the dangers of vaccines. After the experience with polio vaccine came the widely publicized (and heavily litigated) cases of Guillain-Barre syndrome associated with the swine flu vaccine, neurological damage and retardation associated with the whooping cough or pertussis vaccine, and encephalitis, retardation and death associated with the measles vaccine.

Second, victim groups, mostly parents of injured children, have mobilized. With the precedents of the polio cases and numerous other holdings against vaccine manufacturers, they are able to impose enormous financial threats, if not losses, on manufacturers. And some parent groups, such as Dissatisfied Parents Together (DPT), are fighting state mandatory vaccination laws. Immunization is no longer seen as an unmitigated benefit to individuals, and potential victims are less willing to sacrifice their well-being for the common good. In fact, the Davis case is notable for its rejection of aggregate cost-benefit reasoning, or what the court called “a purely statistical point of view.” It said drug companies were not entitled to assume that “‘common sense’ would lead every individual to accept a one-in-a-million risk of contracting polio from the vaccine, even if the risk seems ‘so trifling in comparison with the advantage to be gained.’” The individual must be given a real choice whether to undertake a potentially devastating risk for the collective good.

The third major change in vaccination politics is that the Swine Flu Act set a precedent for the federal government to indemnify manufacturers. From that ex-
perience, vaccine manufacturers learned the strength of their own bargaining position. In the face of epidemics, the public holds the federal government responsible. If manufacturers pull out of the market (as they have done recently with whooping cough vaccine), the federal government is still expected to control the epidemic. Immunizations, for all their potential dangers, are also seen as urgent and essential, and government is under pressure to ensure that they are available. With the AIDS epidemic upon us, the pressure for the federal government to create a victim compensation program and guarantee the supply of vaccines will mount.12

Lifestyle

In the 1970s, the prevention establishment discovered and embraced “lifestyle” factors. In 1972, Belloc and Breslow published the first results from their Alameda County study, showing that the things your mother always said were good for you did indeed lead to greater health and longevity.13 The “good health habits” included sleeping at least seven hours a day, eating breakfast, not snacking between meals, maintaining a reasonable weight, exercising, drinking alcohol in moderation, and not smoking.

In 1974, Victor Fuchs began his highly acclaimed health economics book Who Shall Live? with a parable of two states, in which mortality and morbidity for Nevada and Utah were compared, and the lesson was clear: clean living leads to better health.14 Also in 1974, Canadian health minister Marc LaLonde issued “A New Perspective on the Health of Canadians.”15 The report’s message was that contemporary lifestyles are major contributors to health and disease. Boston’s commissioner of health proclaimed in the New England Journal of Medicine that “the health crisis of today is a lifestyle crisis.”16

By 1979, the American surgeon general had embraced the lifestyle theory in his report, Healthy People.17 Although the report was careful to give equal billing to conventional preventive techniques such as immunization and environmental measures, it devoted far more space and moral fervor to “the matter of individual discipline and will”18 and was widely read as the “‘American Lalonde report.’” It emphasized throughout the “‘actions individuals can take for themselves,’” which included elimination of smoking, reduction of alcohol misuse, dietary changes, exercise, periodic screening for cancer and high blood pressure, and adherence to speed laws and use of seat belts.19

The lifestyle approach, or, as it was often called, the New Perspective, trumpeted individual behavior as the most important influence on health and the factor in disease causation most amenable to change. The surgeon general’s report said that perhaps as much as half of U.S. mortality in 1976 was “‘due to unhealthy behavior or lifestyle,’” and that only about 20 percent was attributable to environmental factors, 20 percent to human biological factors, and 10 percent to inadequate health care.20 Moreover, changing citizens’ lifestyles could be a way
to reduce health care expenditures and other economic losses from disease and death. Thus, the New Perspective was another version of the "free lunch."

The lifestyle approach was immediately attacked in some academic quarters. On one front, political scientists, sociologists, and some physicians saw it as another instance of victim-blaming. Public education campaigns to reform individual behavior diverted attention from more effective prevention strategies that would challenge industry and business. The individualism of the lifestyle approach was criticized as a standard liberal response to social problems, as an attempt by industry to avoid safety and environmental reforms and to escape financial responsibility for the health consequences of dangerous working conditions and pollution, and as the inevitable response of a capitalist government dominated by business interests.

On another front, the lifestyle approach was attacked as scientifically invalid, or at least unproven. One by one, the supposed correlations between health and patterns of exercise, diet, alcohol consumption, and high blood pressure were challenged. Critics usually questioned the methodology of the studies, but a few turned the argument on its head and claimed that the supposedly healthy behaviors actually cause diseases or injuries. Exercise causes injuries and perhaps even heart attacks, low cholesterol levels are associated with cancer, smoking has a protective effect against some kinds of cancer, and seat belts kill more pedestrians (because belts make drivers more confident and they drive more recklessly).

But for all the criticism from social scientists and parts of the medical community, almost everyone agreed that there was nothing wrong with promoting "healthy behaviors" so long as the scientific evidence was good and other occupational and environmental reforms were carried out. Now even that consensus is unravelling as the health promotion strategy takes concrete forms.

On the one side are commercial insurance companies, public insurance programs, and employers, who want to use the new evidence about lifestyle and health (however questionable) to lower their costs. They want to design financial incentives and eligibility requirements to alter people's behavior. On the other side are the individuals to whom these policies are directed—primarily employees, insurance policy holders, and potential recipients of public insurance benefits. They and their advocates see economic and political harms caused by the use of lifestyle factors in employment and insurance. Because of this conflict, three policy battles are likely to loom large in the next decade.

The first is whether lifestyle factors can and should be used as actuarial risk factors in setting insurance premiums. In 1976, Robert Veatch proposed that smokers should pay more for health insurance in any national health insurance scheme, since their behavior generates excess health care costs for the community of insureds. Because all insurance distributes the costs of illness over a pool of contributors, shifting them from the sick to the well, the logic applies to any kind of health insurance, not simply national health insurance. Indeed, the sur-
geon general's report picked up this theme and advocated that insurance companies should offer "preferential rates on life and health insurance to groups engaged in health promotion programs at the worksite." A more recent proposal would rate life and health insurance premiums by "modifiable risk factors," such as alcohol abuse, smoking, cholesterol levels, and hypertension, and would monitor these factors with "objective measures": blood serum level of hepatic enzymes for alcohol abuse, questionnaires and carbon monoxide content of expired air for smoking, blood serum level of lipids for cholesterol, and blood pressure measurement for hypertension.

Actuarial use of lifestyle factors—especially smoking, obesity, exercise, blood pressure, and alcohol consumption—is likely to be challenged under antidiscrimination statutes, notably Section 504 of the 1973 Rehabilitation Act and various state laws prohibiting employment discrimination on the basis of handicap. (As of 1983, 41 states and the District of Columbia had such laws.) The use of gender as an actuarial risk factor in health and retirement insurance has already been curtailed by the Supreme Court. Although the gender cases were decided under Title VII of the Civil Rights Act, which makes gender but not handicap a protected class, the court's rationale is pertinent to the use of lifestyle and other "risk factors" in insurance rating. The first major gender case in this area concerned an employer-operated pension program which (like virtually all pension plans) levied higher premiums from women than from men, because women as a group live longer than men and so draw more in pension benefits. The court noted that Title VII's focus on the individual is "unambiguous":

Even a true generalization about the class is an insufficient reason for disqualifying an individual to whom the generalization does not apply. That proposition is of critical importance in this case because there is no assurance that any individual woman working for the Department will actually fit the generalization on which the Department's policy is based.

Interestingly, the court used the common insurance practice of not rating people by lifestyle factors as part of its justification for eliminating gender:

... when insurance risks are grouped, the better risks always subsidize the poorer risks. Healthy persons subsidize medical benefits for the less healthy ... persons who eat, drink or smoke to excess may subsidize pension benefits for persons whose habits are more temperate. Treating different classes of risk as though they were the same for purposes of group insurance is a common practice that has never been considered inherently unfair. To insure the flabby and the fit as though they were equivalent risks may be more common than treating men and women alike; but nothing more than habit makes one "subsidy" seem less fair than the other. (Emphasis added.)

Since the focus of the Rehabilitation Act and state fair employment statutes is undeniably on the individual, and since the associations between lifestyle fac-
tors and illness are statistical generalizations, the arguments against permitting actuarial use of lifestyle factors are strong. Moreover, obesity, hypertension, alcoholism, and smoking have already achieved some recognition as handicaps under either the federal Rehabilitation Act or state fair employment statutes.30

The dangers of being labeled “high risk” are not lost on victims, and handicapped rights groups have been extremely active in promoting state legislation to prohibit underwriting discrimination on the basis of physical and mental impairments or other medical risk factors. Within one year of the Food and Drug Administration’s licensing of the AIDS antibody test, gay rights groups in California obtained a statutory prohibition on its use in life and health insurance applications. Twenty-six states now have some limits on the use of physical or mental impairment in actuarial rating.31 As litigation under the Rehabilitation Act and fair employment statutes moves more conditions under the protective umbrella of “handicap,” insurors will have to justify their rating practices with better statistical data, and may be prohibited from using some categories at all.

The second battle over lifestyle factors will be whether people can be denied eligibility for disability insurance benefits because they have contributed to their own disabilities through unhealthy behaviors. Disability pension programs usually exclude coverage for conditions which an individual has “willfully” brought on or which are remediable by medical treatment that the person refuses. At the same time, a major tenet of the lifestyle approach is that many of the causal factors of illness are within the control of the individual.

In the aftermath of the rise in Social Security disability pensions during the 1970s and the general political climate for “cutting back the rolls,” lifestyle factors could be a convenient lever for reducing expenditures of disability programs. The rationale of the lifestyle approach has already been used by the Social Security Administration to deny disability benefits in cases where a claimant “refuses to stop” smoking or drinking, “fails to lose weight,” “fails to control” diabetes with diet, or “fails to control” hypertension with medication.32 Very little is known about the extent to which disability insurance programs use these factors to disqualify people, but this dark side of the lifestyle approach is apt to become more prominent as budget deficit worries mount.

Finally, the third battle over lifestyle factors will be whether people who engage in the so-called unhealthy behaviors will be treated punitively or protectively in the labor market. The lifestyle approach’s attribution of individual responsibility and application of deterrence is directly at odds with the new civil rights approach embodied in Section 504 of the Rehabilitation Act and state fair employment statutes. Conditions that are seen as behavioral choices in the lifestyle approach are viewed in the civil rights approach as handicaps beyond individual control, and therefore meritting special protection.

Historically, employers have often refused to hire people who are hypertensive, obese, diabetic, or alcoholic.33 In the last ten years, there has been extensive litigation over this issue, primarily under state fair employment laws but also
under Section 504 of the Rehabilitation Act. Increasingly, employers have been barred from excluding job applicants on the basis of hypertension, uncontrolled diabetes, obesity, alcoholism, and drug addiction, although these conditions are not always treated as handicaps. In general, once a condition is recognized as a handicap (by applicable law), an employer cannot exclude an affected employee unless the condition actually prevents him or her from safely doing the job. Thus, a city which employed diabetics was not allowed to fire a worker with "uncontrolled" blood sugar levels without showing that uncontrolled diabetics were more susceptible to injury on the job than controlled diabetics. Courts seem to be carefully scrutinizing firings and refusals to hire based on an employer's fear of higher insurance costs, and are generally requiring a tighter connection between a medical condition and ability to perform a job in the near future.

Academic fears about the victim-blaming entailed in the lifestyle approach have proved to be well founded. A great deal of punitive, deterrent, and cost-saving policy is carried out through discrimination in insurance premiums and coverage, denial of disability benefits, and denial of employment. But the lifestyle approach has not been implemented without a fight. Through litigation and the protections of new handicap discrimination laws, the victims of these policies are staging a resistance.

Screening

Screening was the clarion call of health reformers of the 1960s. More than any other aspect of preventive medicine, it was peddled as a "free lunch." It would simultaneously broaden access to health care (because mass screening programs would reach out to populations who do not routinely use medical services) and lower the nation's health care expenditures (because screening would detect diseases at early stages, when they are less costly to treat). Like so many health reforms, large-scale screening was supported by a coalition of fiscal conservatives and social services liberals.

There was support for making screening both more intensive and more extensive. The code word for intensive screening was "multiphasic." Touted by public health advocates such as Lester Breslow and Sidney Garfield, multiphasic screening was an extensive physical examination that included a battery of urine and blood tests (aided by the new automated analyzers), x-rays, an electrocardiogram, and hearing and vision tests. The results were conveniently summarized for the physician in a computer printout, complete with normal ranges for each test. Multiphasic screening, it was claimed, would reduce morbidity and mortality and educate people about proper use of the health care system. Under closer scrutiny, the only thing it accomplished for sure was an increase in testing and hospitalization.

The demand for extensive screening found its expression in Congress. Senate and House committee reports emphasized the need to create awareness of existing
health services and stimulate their use. President Johnson's message to Congress in 1967 called for a massive screening program for children: "The problem is to discover, as early as possible, the ills that handicap our children. There must be continuing follow-up and treatment so that handicaps do not go neglected." Congress obliged him by passing what must surely be the least euphonious of the War on Poverty programs—Early and Periodic Screening, Diagnosis and Treatment (EPSDT).

Under EPSDT, the states were supposed to identify medically needy children receiving Aid to Families with Dependent Children (AFDC), inform them of their eligibility for a medical exam, screen them to "ascertain their physical or mental defects," and provide treatment under Medicaid. The story of EPSDT has been elegantly told by Anne Marie Foltz. Suffice it to say that the states and HEW quickly discovered that identifying disease in children generates demand for medical treatment, and that treating poor, sick children costs money. Federal and state bureaucrats stalled, delayed, and constricted the program in every way possible.

EPSDT was a mass screening program whose scope and standards were set by government and whose funds came explicitly from federal appropriations. During the 1970s, the nation engaged in another mass screening program, but one driven by the medical profession and medical research community rather than by explicit governmental adoption—the campaign against hypertension.

The campaign was launched by the National Heart Institute in 1972 in the form of the "National High Blood Pressure Education Program." Besides a physician and patient education effort, the campaign involved mounting several large-scale studies to evaluate the impact of hypertension on morbidity and mortality and to study the effectiveness of various treatment regimens. It was conducted by newly formed interdisciplinary, multihospital, and even international research groups, with names like "Hypertension Study Group of the Inter-Society Commission for Heart Disease Resources," "Joint National Committee on Detection, Evaluation and Treatment of High Blood Pressure," and "Hypertension Detection and Follow-up Program Cooperative Group." The Americans had allies among professional groups in Britain, Canada, Australia, Norway, and Finland. Needless to say, the surgeon general joined the campaign, with a recommendation in Healthy People of periodic screening for high blood pressure.

By the early 1980s, reports from the battlefield were mixed. Most studies confirmed the conventional wisdom that populations with lower blood pressure have a lower incidence of cardiac disease. But it is still not so clear whether screening and treatment make a difference. There are serious problems with defining and measuring high blood pressure—for example, readings on an individual vary significantly at different times. The studies give conflicting results about whether antihypertensive drugs and even low-salt diets are effective in reducing blood pressure. The drugs have side effects unpleasant enough to lead many people to stop treatment. And, as has been found with other screening programs, the mere
diagnosis of hypertension for people who are asymptomatic seems to lead to higher levels of worry, reported pain, and even absenteeism from work.46 One of the fanciest cost-benefit analyses ever conducted estimated that an additional year of healthy life gained by treating hypertension might cost anywhere from $2,300 to $14,900 (in 1975 dollars), depending on the assumptions used in the model.47 These figures, of course, were trotted out to generate skepticism about the value of a mass antihypertension campaign.

With the experiences of EPSDT and the hypertension campaign behind us, a health reformer in 1986 is unlikely to promote screening with the unabashed enthusiasm of his or her predecessors. "Fishing expeditions" for disease among broad populations are rarely advocated now.48 Concern with the accuracy of diagnostic tests and the impact of false positive diagnoses has been heightened, first by the relatively contained internal professional debate over Pap smears and mammography49 and recently by the more public debate over the AIDS antibody test.

In addition to past experience, two important technological changes in the character of screening tools have altered the politics of screening. First, the real burgeoning of screening has occurred not in child or adult health or in automation of tests, but in the realm of prenatal diagnosis. Through amniocentesis, it is now possible to detect Down’s syndrome, Tay-Sachs disease, spina bifida, blood clotting deficiencies, sickle cell anemia, thalassemia, phenylketonuria (PKU), Lesch-Nyhan syndrome, muscular dystrophy, some forms of diabetes, Huntington’s chorea, and some heart disease. A new technique called chorionic villi sampling promises to make these diagnoses much earlier in the pregnancy than amniocentesis has allowed.

The capacity for prenatal diagnosis, mostly yet unmatched by corresponding cures, has brought several new groups into the debate over screening. Ethnic groups are mobilized because some of the genetically linked diseases tend to be concentrated in them (for example, sickle-cell anemia among blacks, thalassemia among people of Mediterranean descent, Tay-Sachs disease among Eastern European Jews). Religious groups are mobilized over the abortion issue, since prenatal screening for untreatable diseases is often linked with selective abortion. Similarly, antiabortion groups are drawn into the conflict. And finally, handicapped rights groups and disease-based interest groups (e.g., parents of children with spina bifida, or people with multiple sclerosis) enter the fray because of their interest in how society treats people with the same disabilities. For different reasons, each of these groups has opposed mass screening programs, or has at least sought to limit them.

Tay-Sachs is an irreversible disease that causes seemingly normal newborn infants to decline into a vegetative state and die within two or three years of birth. Between 1970 (when detection of the carrier state and diagnosis in utero became possible) and 1975, more than sixty screening programs were established in five countries, and over 100,000 Jews had been screened for carrier status in the
United States. But screening has not always been welcomed with open arms by the Jewish community. There has been an intense debate among rabbis and scholars of Jewish law as to whether screening and/or abortion of fetuses with Tay-Sachs disease should be permitted. The stringent branch of the Orthodox tradition—also the dominant and most influential strand of Jewish legal thought—allows screening only of unmarried and not-yet-engaged persons to aid them in their choice of spouse, but strenuously objects to mass screening programs, screening aimed at married or engaged couples, and selective abortion.

Some Jewish public health advocates oppose Tay-Sachs education programs as well as screening. They fear that the stigma associated with genetic disorders may give "apparent confirmation to age-old prejudices about racial debility," and that the information given to individuals about their carrier status may discourage intermarriage in a "population where fertility is already well below replacement, outmarriage is approaching 40 percent, and cultural continuity has depended on reproductive continuity." In several communities, initial plans for a screening program have been curtailed or abandoned.

Screening for sickle-cell anemia has raised similar issues. People identified as carriers in early screening programs often believed themselves to be sick and were sometimes denied life insurance or employment because of the trait. This phenomenon came to be called "nondisease," and it has been identified in other genetic screening programs as well.

Stimulated by this experience of sickle-cell programs, the biomedical ethics think tanks (such as the Hastings Center and Georgetown's Institute for Biomedical Ethics) have generally acted as a restraining force in the adoption of new genetic screening programs. They have developed criteria for morally acceptable genetic screening programs—criteria which put a higher burden of justification on programs that disproportionately affect racially discrete groups and/or groups that have suffered historical discrimination.

Screening has also been linked with the issue of handicapped rights. In the case of spina bifida and other neural tube defects, for example, the possibility of prenatal detection is seen as a mixed blessing by advocacy groups (mostly composed of parents of children with spina bifida). Testing and selective abortion, they fear, may encourage a cult of "perfect children," devalue the satisfying lives of people with disabilities, and deny the genuine strengths and joys of families with disabled children. They also fear that a general social policy of trying to eliminate a disease will only exacerbate discriminatory attitudes towards disabled people. These advocacy groups monitor new developments in testing, provide their input to the Food and Drug Administration as it licenses new tests, and try to ensure that states make testing and neutral information available to prospective parents but do not make screening mandatory. In general, they are a force for caution and restraint in prenatal screening.

Perhaps even more explosive than prenatal diagnosis is the variety of new tests aimed at identifying a "predisposition" to a disease rather than the disease itself.
Some of these tests involve identifying genes or genetic markers. For example, serum alpha-1 antitrypsin deficiency (SAT) has been associated with increased sensitivity to pulmonary irritants; G-6-PD deficiency is associated with increased sensitivity to hemolytic (blood-destroying) chemicals; and HLA-B-26 is associated with ankylosing spondylitis, an arthritic back disorder. Cancer-disposing genes have been identified for retinoblastoma, Fanconi’s anemia, and xeroderma pigmentosum. Some screening tests involve far more common disorders, notably, lower back x-rays to identify people with a high risk of back injury. Other risk screens involve the application of epidemiologic evidence to an individual, so that, for example, an overweight smoker with severe high blood pressure is deemed to be at high risk for cardiovascular disease.56

These tests and the reasoning behind them have created a new medical status somewhere between health and disease—the status of being “at risk” or “hypersusceptible.” Within clinical medicine, the high-risk status usually entails additional medical scrutiny and attention, more intensive examination, and greater follow-up care. But outside the clinical setting, in the less forgiving arena of the competitive labor market, the new medical status is a political and economic liability.

Employers want to use medical screening for risk factors as a way of controlling their costs. They hope that by eliminating high-risk or hypersusceptible workers from their workforce, they will reduce absenteeism, long-term health problems, health and disability insurance costs, worker’s compensation payments, and potential liability for occupational accidents. There is very little information on how many companies actually use medical screening for purposes of employee selection and cost saving. Information is hard to obtain because of adverse publicity about screening as well as fear of litigation under handicap discrimination statutes. But it is clear that medical screening is widespread: according to an HEW survey, preplacement exams are required for 19.2 percent of employees in small firms (8–249 workers), 48.9 percent of employees in medium-size firms (250–500 workers) and 83.3 percent of employees in large firms (over 500 workers). In certain industries, including petroleum and coal products, primary metals, and transportation, required preplacement exams cover over 90 percent of employees.57

Medical screening of employees to improve work efficiency and to save money on insurance is by no means a new idea. Employer-sponsored medical examinations began around 1910; by 1917, more than 10 percent of the 300 largest corporations conducted employee exams. At that time, unions already feared “blacklisting” of workers with health defects.58 The prospect of disability insurance payments led insurers—whether they were employers, commercial companies, or public programs—to seek screening of potential claimants. Thus, it is no accident that employer-sponsored medical examinations were begun as worker’s compensation programs were started, that insurance companies were among the promoters of annual physical examinations, and that mandatory chest
x-rays for World War II military recruits were billed as a way to save money on veterans’ disability pensions.\textsuperscript{59}

But what \textit{is} new in contemporary labor policy discussions is the idea of identifying people who are \textit{likely to develop} a disease rather than those who actually have a current medical problem. Moreover, this new version of the “prevention equals savings” equation amounts to a party line within the profession of occupational medicine. The idea that medical screening of high-risk employees can save money is a virtually unchallenged assumption in the pages of the \textit{Journal of Occupational Medicine}, the organ of the American Occupational Medicine Association. One example will give the flavor of this oft-repeated conventional wisdom:

The physical examination, as part of a risk assessment, is an appropriate and defensible tool for employers to use in evaluating applicants for employment, particularly handicapped persons or disabled veterans.\ldots In terms of business economy, this method fosters sound practices since it can reduce the rate of injuries or illnesses due to inappropriate placements. Optimally this can lead to reduced absenteeism, increased productivity, and decreased expenditures for workers’ compensation and group health insurance. In addition, it may also reduce the potential for litigation brought against organizations for knowingly and negligently placing uniquely sensitive individuals in environments that may cause harm.\textsuperscript{60}

Medical screening, a broad term covering preemployment medical examinations, screening of new hires for specific job assignments (often called “pre-placement” as opposed to preemployment exams), and periodic medical surveillance of a workforce, will become a preeminent issue for labor. The issue has already attracted extensive congressional hearings, an Office of Technology Assessment study, a National Research Council Report, and a \textit{Newsweek} cover story.\textsuperscript{61} As medical screening becomes a way of allocating jobs, particularly high-paying jobs involving risks to health, workers’ interests in obtaining and holding jobs will conflict with their interests in their own health as well as with employers’ interests in health and disability cost control.

So far resistance to medical screening has been staged mainly in the courts using the tools of civil rights, primarily Title VII of the Civil Rights Act and Section 504 of the Rehabilitation Act. Title VII comes into play when a test has a disparate impact on a racial or ethnic group. Most of the genetic characteristics allegedly predictive of hypersusceptibility to toxic chemicals are differentially distributed by race and national origin. Sickle-cell trait and anemia are found primarily among blacks (7 to 13 percent have the trait), and only rarely among whites. SAT deficiency is most common among people of Northern European origin (of whom perhaps 5 to 10 percent have the trait). G-6-PD deficiency was found in one study to affect 16 percent of black American males but only 0.1 percent of white American males.\textsuperscript{62}
The experience with sickle-cell screening foreshadows what may well develop with other genetic tests for hypersusceptibility. By the late 1970s, sickle-cell trait had been associated with over forty pathological clinical conditions, at least two of which were used to deny jobs to sickle-cell carriers. The armed forces and Air Force Academy would not allow carriers of the trait into flying and diving occupations because of an alleged increased risk in deficient oxygenation of blood. And at least one chemical company (Dow) kept carriers out of jobs involving exposure to hemolytic agents, on the theory that they are more susceptible than noncarriers. Both the Air Force and Dow Chemical backed down on using sickle-cell trait as a preemployment screen in the face of media publicity. At least one Equal Employment Opportunity Council decision has disallowed a blanket policy of rejecting all applicants on the basis of sickle-cell anemia, and several states moved to prohibit employment and insurance discrimination based on sickle-cell trait.63

Medical screening faces an even tougher challenge under handicap discrimination laws. Even though the Rehabilitation Act of 1973 applies only to employers having federal contracts or receiving federal assistance (Title VII applies to all employers), its definition of “handicap” is broad enough to cover virtually any form of hypersusceptibility, regardless of its distribution among racial and ethnic groups. A person is handicapped for purposes of this law if he or she has a physical or mental impairment that substantially limits a major life activity, has a record of such an impairment, or is regarded as having such an impairment.64 Whether this law applies to the new status of “high risk”—i.e., the employee is at risk of future harm and therefore is not hired because an employer fears future costs—is still an open question. But a substantial body of legal scholarship suggests that protection should and will be afforded the high-risk employee.65 State fair employment statutes offer protection as well. And with those windows of legal opportunity open, it is sure that medical screening for purposes of employee selection and placement will be resisted by labor, especially when and where unemployment remains high.

**Occupational safety and health**

The Occupational Safety and Health Act of 1970 is one of the most controversial pieces of regulation ever passed. Throughout the 1970s, it stood at the center of a raging debate on the scope and effectiveness of government. The issues were cast as “government versus the private sector” and “safety versus cost.” Can government effectively regulate millions of management decisions in hundreds of thousands of locations? Is it better to use mandated standards or economic incentives to promote change? How strict should safety standards be? How safe is safe enough? How should cost concerns be balanced with health and safety concerns?

Labor and industry fought for the program’s soul—the design requirements and exposure levels incorporated in its standards. Labor played the role of tough
cop, watching the Occupational Safety and Health Administration (OSHA) for any signs of giving in to the more lax standards desired by industry. Labor leaders saw red whenever industry purported to trade off worker well-being for cost saving or the promise of general economic prosperity. For labor, any risk with workers' bodily health was too much risk. Companies and trade associations watched OSHA with equal attentiveness. They formed the American Industrial Health Council to promote the idea that risk is a "fact of industrial life" and therefore "socially acceptable." And they went straight to the White House to plead their case, whence they obtained restraints on OSHA in the form of required "economic impact analyses" and new layers of regulatory review controlled by the White House and the Office of Management and Budget. In short, occupational safety and health was an area of prevention policy where all the political actors behaved true to character, no matter whether one viewed the drama from a pluralist or a Marxist perspective.

The concept of hypersusceptibility challenges the underlying premise of the legislation—namely, that it is possible to set a standard for exposure to a hazard which will protect all workers from dangers to their health. The premise of hypersusceptibility is that there are some people whose inner defenses are weakened or compromised, so that only a lower level or no exposure would protect them. On the question of exposure levels, traditional politics still hold: labor would like to see standards set to a level protective of the most vulnerable worker, while industry would like to have standards protective of the average worker combined with screening to exclude more susceptible workers.

But labor—from the staunchest leaders to the men and women on the shop floor—knows that exclusion of unhealthy or weaker workers is a longstanding reality in the labor market. As Anthony Mazzocchi testified in hearings on the lead standard, "Job security is foremost in mind to the people we represent. It probably is foremost in the minds of most workers. Their experience demonstrates adequately that if they suffer abnormality on the job, they are removed." Nor are workers with even mild health problems likely to be hired in the first place. The "prevention equals job loss" equation was chalked on the national blackboard in 1979 when the New York Times broke a story about American Cyanamid's policy of excluding fertile women from its pigment department because of exposure to lead dust that could be harmful to fetuses. Five women underwent sterilization to avoid transfer to lower-paying jobs. It soon became known that many companies barred fertile women from certain jobs involving toxic exposure.

The issue of "reproductive hazards," as it is politely called, brought home to labor, women, and civil rights groups that a policy of exclusion of "high-risk" workers could adversely affect an enormous number of people. In the case of lead, industry leaders insisted on excluding not only pregnant women but all fertile women, because lead builds up in the body and could damage a fetus before a woman knew she was pregnant. If that kind of reasoning were applied to other
toxic hazards, millions of women in the labor force could be affected, since well over two-thirds are of child-bearing age. About 20 million jobs involve exposure to potentially fetotoxic chemicals. And more and more evidence suggests that reproductive and fetal harms occur through male exposure as well as female.\[^{71}\]

OSHA spearheaded an investigation into these exclusionary practices, joined by the Equal Employment Opportunity Commission and the Office of Federal Contract Compliance. The broad-based Coalition for Reproductive Rights of Workers attracted the major unions (United Steelworkers, United Auto Workers, United Rubber Workers, Oil, Chemical and Atomic Workers Union, and many others), women's organizations (e.g., National Organization of Women, League of Women Voters, and Women's Legal Defense Fund), civil rights organizations (American Civil Liberties Union and National Lawyers Guild), and reproductive rights groups (Planned Parenthood, the Alan Guttmacher Institute, and the Committee for Abortion Rights and Against Sterilization Abuse).

The coalition sought some kind of ban on exclusionary policies. In general, members adopted the traditional labor view that employers should provide a safe workplace, but given the realities of many unsafe jobs, they supported the right of the individual woman, rather than her employer, to choose whether to accept the risks of exposure in a particular job. They also sought to borrow a new remedy from the area of toxic substance regulation, something quite different from the traditional OSHA tool of engineering redesign or the traditional industry policy of exclusion. The new remedy was called "medical removal protection with rate retention" and it involved transfer of a susceptible worker out of the dangerous situation while protecting his or her pay level, seniority rights, and fringe benefits.

The coalition failed in its immediate goals. The EEOC issued some proposed guidelines which generally frowned on exclusion of women without solid evidence that paternal exposure does not contribute to fetal harm, and in any case allowed exclusion only of pregnant women, not all fertile women. But they did not provide medical removal protection. The guidelines were attacked by industry, labor, and women's groups alike, and in the end were withdrawn by the Reagan administration as part of a general undoing of the Occupational Safety and Health machinery.

Nevertheless, the reproductive rights controversy shaped the terms of the debate over occupational safety and health for years to come. Most of all, it highlighted the way the high-risk worker concept forces a choice between job security and high pay on the one hand and future health on the other. It dramatized the potential for the concept to be applied to almost any worker, not merely a few workers in esoteric jobs. It revealed how the focus of the debate had shifted from the safety of the workplace to the weakness of the individual worker. And it exposed the struggle for power implicit in the question of whether employers or employees would get to decide how health risks and job benefits should be balanced.

It is in this respect that the politics of occupational safety and health have changed. In the earlier debate, health and safety were pitted against job security
only in an abstract way; industry argued that the high costs of safety provisions would force some businesses to close. The concept of the hypersusceptible worker brought the conflict between health and job security down to the level of the individual.

Forced to choose between job and health, workers and their representatives will fight to preserve jobs. Lloyd McBride, president of United Steelworkers, stated the case poignantly at the 1977 hearings on the lead standard and medical removal protection:

It is kind of a human equation, perhaps, but I think it is one that most of us would identify with. If we were confronted as the breadwinner of a family, of tolerating a health hazard, perhaps, in order to continue to provide for our families, most of us, absent from some other way to do it, and the high unemployment economy, there is very little other opportunity for the person in the lead plant to go out and get other employment—faced with that combination of circumstances, I think most of us would put up with the continued health hazard.72

Labor and its allies are now often in the position of advocating less caution in job safety and the right of individuals to work in unhealthy environments. During the lead hearings, a women's advocacy group submitted testimony that pregnant women should be allowed to decide whether to work in environments dangerous to the fetus; in the 1940s, by contrast, the Women's Bureau of the Department of Labor sought automatic transfer of all women exposed to substances harmful to the fetus.73 In 1981, workers at risk in an Idaho lead smelter requested that the plant be exempt from OSHA standards, the very standards labor had sought to tighten during the hearings.74

OSHA has promulgated 21 toxic substance standards that require employers to monitor their employees' health. These standards, covering asbestos, lead, benzene, vinyl chloride, cotton dust, coke oven emissions, and several carcinogens, generally require employers to conduct preplacement medical examinations, use the information to match employees to "suitable" jobs, and conduct periodic medical examinations ("medical surveillance") with a specified set of tests on all workers exposed to concentrations above a defined "action level."75 But for the most part, the standards do not say what an employer should do if an applicant is found unsuitable for a proposed assignment or if an employee is found unable to bear continued exposure. Only three of the standards (lead, vinyl chloride, and asbestos) include medical removal protection (that is, transfer to another job), and only one (lead) also provides for rate retention.76

The hypersusceptible worker is thus in a no-man's land of social policy. He or she may be medically unemployable by informal company policy or by OSHA standards, but ineligible for any of the available forms of disability insurance—company plans, Worker's Compensation, or Social Security Disability Insurance. These insurance programs typically require that a claimant be physically or
mentally unable to work (the Social Security definition requires total and permanent disability) or have sustained an actual injury caused by work (Worker's Compensation). The hypersusceptible worker is quite capable of working but is deemed by company medical personnel or OSHA standards to be at high risk of becoming disabled.77

If the occupational safety and health issue during the 1970s and early 1980s was cast as a struggle over the proper cost-benefit balance, the struggle of the next decade will surely be over medical removal protection and rate retention, or other ways of providing for the medically unemployable but nondisabled worker. In a larger sense, the struggle is over access to jobs and job security. It is a bitter irony that precisely when some politicians are bemoaning the growth of disability rolls and the decline of the work ethic, workers are fighting to stay in their jobs, resisting medical examinations and transfers, in the face of private and public policy that would render them unemployable "for their own good."

Conclusion

A review of prevention policy over the last two decades reveals a striking pattern. In each of the major areas of preventive medicine, enthusiasm for large-scale adoption of public health techniques ran into resistance by the very people prevention was supposed to help. In each area, the resistance was triggered by the "beneficiaries" discovery that they had been harmed by a preventive measure. The harms might be physical (the disease and disability caused by vaccines), psychological (the stigma and anguish associated with genetic screening), economic (the inability to get a job, keep a job, or obtain insurance because of being classified as "high risk"), or social (the setbacks for women and blacks in the labor market as they were found to be at risk and potentially costly to their employers; the subtle harms to the sense of community caused by genetic and prenatal screening).

The politics of preventive medicine described here manifest the strong individualism so deeply ingrained in American politics in general. Philosophically, the whole idea of identifying high-risk individuals and high-risk individual behaviors locates the source of misfortune in the individual rather than in social structure and economic opportunity. Practically, the idea undermines social insurance, the very keystone of the modern welfare state.

Social insurance is based on risk pooling, cross-subsidization, and what the Germans call "the solidarity principle": individuals may pay for more or less than what they actually get back from social insurance, but those transfers are what make a group a community and not just a collection of strangers. In a community, individual misfortunes are a group problem.

Collective responsibility does not sit comfortably in the American political ideology. The United States has always been a laggard in social insurance, whether for industrial accidents, old age pensions, health care, or family needs. The con-
cept of the high-risk individual is a subtle way of dismantling protective insurance. With it, we shuck off people one by one, throwing them out of the risk pool for health insurance, disability pensions, or life insurance, and out of the applicant pool for jobs.

Thus cast off, individuals resort to the one sort of protection American society finds legitimate and acceptable—civil rights. That is the one form consistent with individualism. Civil rights policy is based on the principle that one stands or falls on one’s own merits. A person may not be treated according to, or have his life chances determined by, group characteristics that have no relation to individual achievement—race, gender, age, and now physical health. With the tools of civil rights, citizens fight the harms of group classification inherent in the lifestyle, screening, and occupational safety approaches to prevention.

Even in the area of immunization, individuals fight with private, civil tort actions. And when they win, they win not on the principle that society should compensate them for undertaking risk to benefit the community, but rather on the principle that an individual is entitled to decide for himself. Vaccination is just another frontier where the individual pits his wits against the unknown. (In the wake of the initial polio vaccine suits, preventive medicine advocates developed informed consent procedures for children, so even six-year-olds could stake their fortunes on an experimental trial of swine flu vaccine.)

That prevention should be resisted is thus entirely understandable. If it is ever to be widely accepted, prevention must take into account the kinds of harms detailed here and include appropriately designed compensation policies, so that already-disadvantaged individuals do not have to bear the brunt of social progress.

Notes
1. See especially Louise Russell, *Is Prevention Better Than Cure?* (Washington, DC: Brookings Institution, 1986), a comprehensive review of cost-benefit studies of prevention. Russell’s major message is that the claims being made for prevention as a way to cut medical costs are generally untrue. Russell is careful to note that prevention “can be a worthwhile investment in better health, and this—not cost saving—is the criterion on which it should be judged” (p. 5). But the burden of the book is certainly to show that prevention does not save money.
4. Interview with author, 16 April 1986.
7. Davis v. Wyeth Laboratories, Inc., 399 F.2d 121 (9th Cir. 1968), and Reyes v. Wyeth Laboratories, 498 F.2d 1264 (5th Cir. 1974). For extensive discussion of these cases, see Hardin, “Poliomyelitis Vaccine”; Institute of Medicine, “Vaccine Supply and Innovation,” chapter 7; and Mary Elizabeth Mann, “Mass Immunization Cases: Drug Manufacturers’ Liability for Failure to Warn,” *Vanderbilt Law Review* 29 (1976): 235–66.

9. For a review of vaccine complications and estimates of their likelihood, see Institute of Medicine, "Vaccine Supply and Innovation," chapter 5. Chapter 7 reviews vaccine litigation.


12. The Institute of Medicine report "Vaccine Supply and Innovation" calls for some kind of national victim compensation system and a resolution of the unstable liability situation in order to assure a continued supply of vaccines. The report offers several options.


18. Ibid., p. viii.

19. Ibid., p. 10.

20. Ibid., p. 9.


29. Ibid., p. 710.

30. See note 35 below.


38. This "have your cake and eat it, too" logic is the key to the coalitions behind many health reforms, not merely prevention. HMOs were going to increase access and lower costs by organizing delivery more efficiently. See Paul Starr, "The Undelivered Health System," The Public Interest 42 (Winter 1976): 66–85. DRGs were going to do the same by cutting out "unnecessary" hospital services. See James Morone and Andrew Dunham, "Slouching Toward National Health Insurance," Yale Journal of Regulation 2 (Winter 1985): 263–91. Health planning would work its magic by cutting out unnecessary facilities. Professional standards review organizations (PSROs) would simultaneously increase quality of care and lower expenditures by eliminating unnecessary services.


42. Anne Marie Foltz, An Ounce of Prevention (Cambridge, MA: MIT Press, 1982).

43. For an excellent description of this campaign, see Russell, Is Prevention Better Than Cure? chapter 3. I rely on her book for my account.


45. For a review of this literature, see Russell, Is Prevention Better Than Cure? pp. 49–56.


51. For my summary of this debate in Jewish law, I rely on Ronald M. Green, "Genetic Medicine in the Perspective of Orthodox Halakah," Judaism 34 (Summer 1985): 263–77.


56. Most of these tests are the subject of scientific controversy, and there is a substantial degree of opinion that they are not suitable for use as preemployment screening devices, either because


70. Company rules were usually worded so that women of childbearing age were excluded unless they could offer medical proof of sterilization or infertility. Companies known to have had such policies include American Cyanamid, Union Carbide, Eastman Kodak, Celanese, Dupont, Allied Chemical, Monsanto, St. Joe's Mineral Corporation (lead smelter), General Motors (battery plant), B. F. Goodrich, Olin, Sun Oil, and Gulf Oil. Donald R. Crowell and David A. Copus, "Safety and Equality at Odds: OSHA and Title VII Clash over Health Hazards in the Workplace," Industrial Relations Law Journal 2 (Spring 1977): 567–95, at pp. 570 and 592; and Ronald Bayer, "Women, Work and Reproductive Hazards," Hastings Center Report 12 (August 1982): 14–19, at p. 15.


75. Rothstein, "Employee Selection," pp. 1414–16, provides a listing of all the standards and their medical surveillance requirements.

76. Rate retention was initially provided in the cotton dust standard, but that part of the standard was invalidated in American Textile Manufacturers Institute, Inc. v. Donovan, 452 U.S. 490 (1981). The court said OSHA had not given sufficient reasons why medical removal protection and rate retention were necessary to protect worker safety and health.