Social Responsibilities of Bioethics

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ABSTRACT *Urban bioethics can draw on elements of city life and view them under the moral perspective of social responsibility of creating the personal, cultural, social, and economic environment in which persons can be responsible personally as they interpret actions on themselves and creatively respond to them in an ongoing community of agents.*

Something funny happened on the way to bioethics. During the first decade of its existence, 1970–1980, bioethics took a right turn and followed a road that was both straight and narrow. It was straight in that it led to a highly successful demi-discipline, the renewal of the ethics of medicine in the new era of medical technology and new forms for the delivery of health care. It was a narrow road in that the emerging bioethics left the broad social and cultural fields within which medicine exists and strode into the close and restricted routes of clinical medicine. While walking its narrow medical path, bioethics could see broad fields on either side and commented occasionally on their significance, but it rarely left its straight road to wander into them. The narrow path was in part a good one to take because it traveled into a territory quite familiar to medicine and to ethics: the place inhabited by the very intimate contacts between individual physicians and individual patients. This was the place where medicine had long dwelt and that it knew best; it was also familiar ground for moral philosophy, which had long meditated on the quality of choices exercised by individuals in relation to other individuals. The destination, then, of early bioethics was a welcome place in which two different human enterprises, medical care and moral philosophy, could begin to converse. That conversation has been a fruitful one in many ways.

Yet, the paths not taken, those into the dark woods of the social environs of medical practice, have deprived bioethics of experiences that would have enriched and perhaps even changed many of its received views about medical ethics. Bioethics has not been a social ethics in any significant way. I recall with some chagrin that, in the 1970s, I wrote an article that challenged the strong appeal of my good friend and current Yale colleague, Dr. George Silver, that medicine was obliged intrinsically to a range of social responsibilities.[1] I championed, in a way I now see as shortsighted, the moral bonds that tied the physician to the patients he or she was treating. In today's remarks, I try to make amends for that early folly. I first explain why the right turn into the narrow path was taken and then suggest some ways to broaden that highway for the bioethics of the next millennium.

In the earliest inklings of bioethics, during the 1960s, scientists and physicians began to raise questions about the impact of technology on human life. Conferences

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and conversations centered on two particular questions. The first was the so-called population explosion, attributed to improved agriculture; the "green revolution"; and the success of medicine, particularly antibiotics, in increasing life expectancy. The second was the prospect for the control of the human genetic heritage, promised by the revelation of the double helical structure of DNA. This prospect not only was exciting, but also was worrisome for it revived the troubling visions of the eugenicists, which although only recently discredited by the increasingly sophisticated population genetics and politically damned by the evil of Nazi racial hygiene, reappeared wrapped in biochemical garb. It must be noted that both these subjects, by their very nature, are saturated with ethical questions of social and communal import. The word *bioethics* was coined in 1970 to designate the study of the moral relationship between humans and their social and physical world.[2] The deliberate manipulation of the human environment and of the human genome is a primal question for social ethics: How should we live as a human community in a world welcome to human flourishing?

However, neither topic moved in that direction. The population question drifted off the agenda of the emerging bioethics as it became a contentious matter for domestic and global politics. The genetics question, while remaining on the bioethics agenda, quickly veered toward problems that de-emphasized a communal ethos in favor of an ethic of personal autonomy. The great philosophical questions raised by genetic engineering were judged by most pioneer bioethicists as futuristic, while the immediate questions of genetic testing and screening, made feasible clinically and epidemiologically by the new science, required intense ethical scrutiny. That scrutiny, colored by revulsion to eugenics, led to a genetic ethic that stressed the right of individuals to protect their genetic information and control their heredity. Thus, the nascent bioethics lost two opportunities to travel toward a social ethic.[3]

In its infancy as a discipline, another question arose that also could have taken a social turn, but did not. A somewhat quiet, intramural discussion about the use and abuse of human subjects in biomedical research attracted the attention of some scientists and administrators of scientific research funding. In 1972, that quiet discussion broke into loud public debate and dismay when the story of the Tuskegee Syphilis Study hit the news. A long examination of the ethics of research ensued. Again, the moral question about research could be posed in social terms: How can the betterment of the population be achieved without putting at risk a few persons? However, this utilitarian formulation was repudiated quickly under the powerful arguments of scholars such as philosopher Hans Jonas and theologian Paul Ramsey. The ethics of human experimentation then was founded on a strong affirmation of respect for the individual person and the need for informed consent. This direction was the appropriate one for the moment since, in the Tuskegee experiments and other notorious examples, persons were used as uncomprehending and coerced means to others' ends. Still, another opportunity for the exploration of a social ethic had bypassed bioethics.

The ethic of personal autonomy became even more pronounced when the debates over life-sustaining treatment began during the 1970s. The Quinlan case, and others like it, drew bioethics into the labrynthine ways of clinical medicine. There, the principal moral mission was to vindicate the patient, subject to the coils of technological medicine and the paternalism of physicians, and make the patient an autonomous decision maker about the quantity and quality of his or her life. Bioethics, during its first two decades, had walked into the medical clinics and wards.

Since clinical medicine is so dedicated to the treatment of individuals, bioethics dwelt on this one part of the moral universe to the neglect of others. Occasionally, it wanders, or even leaps, into the wider world, as it has done in its excursions into the problems of allocation of scarce resources or managed care, but even then, it dwells there only briefly and nervously. It does not seem to be comfortable outside its familiar territory of personal autonomy and interpersonal beneficence and non-malficence.

Of course, even though justice has always been acknowledged as one of the central principles of bioethics, the theoretical heights and depths of this perennial topic of ethics remain very much in the background. Every bioethicist quotes John Locke and John Rawls with reverence, but very few have invited these great philosophers to become more than occasional visitors in their realms. Professor Norman Daniels[4] remains one of the few bioethicists to explore the complex questions of health policy in light of profound philosophical theory. In addition to the narrow philosophical focus, bioethics, from the beginning, has ignored disciplines that explicitly study the social dimensions of human decisions and actions. Although sociologists and anthropologists also showed an early interest in the questions raised by medical advances (particularly in experimentation with human subjects), bioethicists only rarely engaged in serious conversation with these scholars.

These remarks may be superficial and somewhat unfair to bioethics. Yet, I judge them in large part true. Bioethicists have not developed an adequate social theory, and the opportunities offered to do so have not been exploited. The time has come to move onto higher roads. Many new issues draw bioethics onto these roads: Renewed concern over the ethics of genetics, the organization and financing of health care, and the promotion of public health cannot be pursued without a more robust appreciation of social ethics. It is easy enough to say this, but difficult to accomplish. One obstacle in the road is social ethics itself. It is not clear what social ethics actually is. Is it personal ethics writ large, the realization by individuals dedicated to the justice and fairness of social practices and to institutions that are open to the talents of all? Is it a radical redefinition of the person as a social being? Is it an articulation of communitarian ideals and goals? Is it a temptation toward a totalitarian social philosophy? Explorations into social ethics move in all these directions, but have not broken any consistent trail into the complex of concepts and problems that surround the life of the human social animal.

Of course, ethics always has dwelt with these problems. The history of ethics in Western culture is filled with reflections on them. For Plato, the moral life of individuals was a small image of the moral life of the state; for Aristotle, ethics was the prelude to politics. He begins his *Nicomachean Ethics* with the following words:

> Even if the good of the community coincides with that of the individual, it is clearly a greater and more perfect thing to achieve and preserve the good of the community . . . such is the aim of our investigation (into ethics); it is a kind of political science.[5]

Certainly, anyone who has read classical ethics finds innumerable claims about the relationship of persons and society. However, human societies are protean. They constantly change shape. The citizens of the Greek polis would not recognize the citizens of the American nation; the subjects of a Hobbsian Leviathan state would hardly know the subjects of contemporary cool Brittannia. Societies are so different

that it is difficult to apply the wisdom of one to another. It seems easier, although it is probably fallacious, to take up wise thoughts about the mind and emotions of individuals, which seem to sound the same over centuries, than to hear Athenian democracy in the democracy of the United States. Social ethics suffers from this difficulty of translation.

Yet, we must not forget that almost every serious moral philosophy places human life in a social setting. We need to appreciate the social setting of our times and places as the site for moral decision making, and we need to integrate our appreciation of that social setting into the map of moral philosophy. An appreciation of social setting comes in part from scholarly sociology and in part from experienced observation and participation in social life. But, sociology and engagement are not enough for an ethic. An ethic is about what *ought* to be made out of what is, and understanding that this requires more than disciplinary understanding and sharp insight into experience. I do not think that we are sure as yet about quite how to go beyond discipline and experience to formulate a social ethic.

Nevertheless, the understanding of what ought to be begins to appear when we begin to ask consistent questions about the relation between individuals and their social setting and to follow up these questions with partial answers that can be fitted into larger and larger concepts. A theory of social ethics is built piece by piece out of questions and partial answers. So, if we hope to respond positively to the whether bioethics has social responsibilities, we have to begin to reflect on the series of questions and answers that will take us in the direction of a social ethics of bioethics. We must retrace the steps of bioethics back to their beginnings and take note of the turns on the paths that have made that demidiscipline into an ethics of personal autonomy rather than an ethic of social responsibility. We must ask why that turn was taken and whether a different turn could have been taken or, perhaps, find deeper understanding of the implications of that turn.

I have used the phrase *social ethics*. In reference to the purposes of this conference, I should use the phrase *urban ethics*. This phrase sounds odd to ethicists; there is no generally accepted field of urban ethics. Although Aristotle's *Politics* was about urban ethics—after all, politics concerns the polis, the city—the philosophers' reflections generally have been about persons in society, a much broader, more general, abstract relationship. As usually conceived, the social contract creates a civil state, usually a nation-state. The unique form of society, the city, has not inspired modern philosophers to create a peculiar ethical system for urban life.

Indeed, in the United States, the Jeffersonian vision of sturdy yeomen working the land dominated the moral ideals of America for many years, even as more of those sturdy yeomen migrated into cities and became factory workers, businesspersons, and unfortunately, the ever-present urban poor.

Cities gradually became the vital centers of American life. However, when these great accumulations of people and business attracted the attention of social thinkers at the end of the 19th century, it was as caldrons of deprivation and depravity. The American city was less a source of moral ideals than a lesson in moral degeneracy. Extensive literature about urban life has appeared, from the sociological treatises of scholars such as Max Weber, Lewis Mumford, and William White, to the trenchant commentary of literary observers such as Brendan Gill and Jan Morris. Yet, ethicists seem not to have read that literature; indeed, they write as if they almost never even lived in cities. When writing about ethical decisions and actions, they still take a perspective so abstract that it has no space or time dimensions; the ideal, impar-

tial, impassive observer is the rational person in the original position behind a veil of ignorance. How distant from the streets of New York!

I might retrace the steps that bioethics has taken in hopes of finding a path toward urban bioethics. One of the most urban events in recent medical history has been the acquired immunodeficiency syndrome/human immunodeficiency virus (AIDS/HIV) epidemic. Epidemics are, by their nature, usually urban events, but from its first appearance in the United States in 1982, HIV played its cruel scene in two of America's great cities, San Francisco and New York. In part, this was due to the presence in those cities of significant populations of gay men. Yet, the two quite different urban settings shaped epidemics that were idiosyncratic.

As Professor of Bioethics at the University of California, San Francisco, I was much involved in the political, medical, and personal turmoil that surrounded the epidemic. I recall a meeting in 1985 at which a group of persons convened by the Hastings Center, located in New York, visited San Francisco to view our response to the epidemic. They were astonished to find how different the epidemics of San Francisco and New York looked at that time. One significant difference was that the San Francisco gay community, which contained many well-educated and cultured persons, had begun to assume responsibility for the public health measures that might prevent and contain the spread of infection. In New York, the gay community, while politically adept, had not evolved into as coherent a culture as in San Francisco. In addition, in New York, the infection was virulent in other populations, particularly persons addicted to drugs who lived in economic and cultural conditions much less conducive to similar assumption of responsibility. The pathology of the infection was much the same on both coasts; the sociology of the epidemic was quite different.

The ethics of HIV/AIDS quickly took the same bioethical turn I described above. Through a variety of critical problems, it consistently emphasized personal autonomy. This was due, in large part, to the pervasive concern that the stigma of homosexuality would prejudice the social attitudes, financial status, and health care of those who were known to be infected. Many of the traditional public health measures, such as screening and surveillance, either were not applied vigorously or were modified to take account of personal privacy. Measures such as education and personal responsibility were promoted. The increasingly vocal and political influence of gay persons, who were so deeply touched by the epidemic, was felt in the formation of this ethic. One incident, in particular, made this clear to me. The Director of San Francisco's Public Health Department determined to close the city's many bath houses, which provided occasion for frequent sexual encounters between men. This was a strategy of traditional public health in time of epidemic: forbid access to places favorable to the communication of disease. Many leaders of the city's gay community protested, not because they disagreed with the rationale, but because they saw the measure as another example of stigmatization and discrimination, an example of blaming the victim. They contended that education and enhancement of personal responsibility was a more appropriate public health strategy. They could make that case plausibly because there truly was, at that time in that place, a cohesive community, persons who shared values, lifestyles, and even a neighborhood. All had suffered from discrimination due to their sexual preference. Many of that community were infected, and all knew and loved others who were. Also, they were living in a city where general tolerance for distinct lifestyles was rooted and where a new tolerance for gay persons was becoming acceptable. All of

this was an urban phenomenon. The peculiar indifference of city people toward each other implies a grudging respect for those who are different. HIV/AIDS in San Francisco, in those days, was a very urban epidemic.

Certainly, New York's epidemic was equally its own. I do not know it as I knew that of San Francisco. Still, I was part of an event that reveals how ignorance of urban perspectives and ethics can distort public policy. In 1991, I was asked to chair a study of the National Academy of Sciences, the Impact of AIDS on Society. A very knowledgeable committee was assembled that worked for 2 years, gathering data and debating issues. In our final report, we proposed that, at that stage of the epidemic in the US, the impact was going to be felt most heavily among classes already deprived and discriminated against—people of color and those plagued by drug use, poverty, and poor health; women and children disproportionately would be victims. We recommended that public policy turn from broad, general preventive programs to targeted, intense ones among the populations most likely to be attacked. This conclusion outraged the leaders of the HIV/AIDS prevention world. Several condemned the committee's work as irresponsible. They claimed that it would drain the HIV/AIDS prevention programs of public money since Americans had to be convinced that all persons of all classes were equally at risk. The report was buried, and the recommended programs never were initiated.[6] Yet today, almost a decade later, the epidemic has become what our committee predicted: an affliction of those already afflicted.

I believe the committee, unconsciously, had been doing urban ethics. They realized that the structures of communication and familiarity, as well as the networks of identity and interaction that cities provide, would make inflection move in one way rather than another. The opponents of our recommendations seem to have forgotten the primal law of epidemics: Disease thrives in crowded places. They were willing to promote the idea of HIV ravaging the plains and the prairies. The ethics of prevention and containment was misconceived because it was not conceived within the context of urban life. These episodes from one bioethical event represent a broader problem for bioethics: the virtual absence of the urban context from the formulation of almost all bioethical problems. Certainly, the clinical nature of the common bioethical problems does shrink them to close interpersonal relationships. To the extent those relationships play on a social stage, it is the antiseptic social world of the hospital. An occasional bioethical problem opens that world to the outside, such as triage in the emergency department of a city hospital or a neonatal intensive care unit filled with addicted or HIV-infected babies. Even then, the ethical analysis of the problems arising in those situations stays close to the smaller drama. The causal contributions and cultural influences are noted but seldom play an integral part in the story. They are, in the words of an influential text in bioethics, "contextual features."[7]

This is to say that bioethics currently does not focus on social responsibility. Indeed, it does not neglect social responsibility and often evokes aspects of social responsibility in its deliberations, but as a discipline, it puts social responsibility, particularly in terms of the principle of justice, at the margins of its intellectual views. Of course, individual bioethicists possess strong commitments to social responsibility and act on these commitments. Bioethics, however, is not a person who believes and acts on commitments; it is a discipline, a body of ideas to be studied, developed, and taught. It is not an activist movement, rallying advocates in favor of a cause; it is a discourse, prompting and educating people to discuss and debate problems. As discipline and discourse, it has yet to integrate the principle of social

responsibility into its teaching and talking. (One notable example of public bioethical discourse, Oregon Health Decisions, however, did address social responsibility explicitly in the allocation of health care resources.)

How might urban bioethics be built around a strong principle of social responsibility? First, bioethics is a creature of cases: The discipline and discourse began with and has been stimulated constantly by actual cases, which raise moral concerns. Urban bioethics will bring cases from life in the city. It must be careful not to sanitize them, strip them of their urban origins, and convert them into standard bioethical cases of personal autonomy. So, urban bioethics will build a file of cases in which the urban context looms large. Second, urban bioethics must work with an ethical conception that fits the psychological and sociological nature of urban life. If the ethical conception of personal autonomy stems from the Jeffersonian vision of the sturdy yeoman, it will fit the American city dweller uneasily. This is not a denial of the centrality of personal autonomy, but a suggestion that autonomy looks different in central Iowa than it does in Central Park.

One leading American moralist, the theologian H. Richard Niebuhr, articulated a concept of responsibility that might provide a foundation for urban bioethics. Niebuhr, whose academic life was in the sheltered ivy walls of Yale, was raised in the turmoil of industrial Detroit, Michigan. His brother Reinhold was a long-time New Yorker. Both had been involved deeply in the Social Gospel movement of the early 20th century, which saw the city, with its concentrations of wealth and poverty, its industries and its slums, as its mission. Niebuhr proposed that the idea of responsibility was the most fundamental ethical notion. Humans are not merely obedient servants of God, not independent creators of their own world; they are responders to their world of nature and persons. He defined responsibility as "the idea of an agent's action as response to an action upon him in accordance with his interpretation of the latter action and with his expectation of response to his response; and all this in a continuing community of agents."[8(p65)] This is an idea that wonderfully fits urban life. Persons who live in great cities are perpetual responders: Their lives depend on being able continually to interpret the constant action around them, from walking down Fifth Avenue in a crowd to managing the complexities of business in a high-intensity environment. Niebuhr believed that the essence of the ethical was sustaining the ability to respond to responses in ways that could keep the action going in a "continuing community of agents." What is more a continuing community of agents than a city?

Many moral problems of urban life arise from stifling of responsiveness. Persons are in situations in which actions are "upon them," and they are not able, for many reasons, to respond to those actions. They become excluded from the ongoing community of agents. Urban bioethics, in my view, might use this Niebuhrian concept as its foundation and central perspective. It would always ask, as its first question: How can a resolution be found that will open up responsiveness and enhance the ongoing community of agency? Social responsibility is, at root, the moral perspective that promotes responsivity. It incorporates the principle of personal autonomy in the wider community of responsive, responding, and responsible agents.

The community of urban dwellers has another ethical feature: It is not a community of intimates who know and converse with each other and few others. It is a collection of strangers in constant contact, within which some communities of intimates exist. I have referred elsewhere to the ethics of strangers in contrast to the ethics of friends.[9] Niebuhr's comment that agents must interpret actions upon them entails that the responses to strangers will be formulated quite differently

from those to friends. Suspicions and indifference anticipate the responses of strangers; certain social rules are devised to give some form to expectations of the stranger's response. In city life, strangers will brush constantly against strangers, sometimes even carrying on extended dealings, but remaining strangers. The moral challenge consists of the support of responsivity among strangers. This is one of the virtues of a successful city.

Last month, I was entranced by the PBS documentary, *New York*. A central episode told the tragic story of the terrible Triangle fire in 1911, in which 150 young women, mostly teenagers and immigrants, were burned to death because they had been locked into their unsafe garment factory. As laborers, they were incapable of response to the actions upon them: They were passive objects of exploitation. After the fire, the voices of sweatshop workers began to be heard; the public responded to their plight. Certain powerful political leaders, such as Al Smith of Tammany Hall, responded; his voice elicited the response of government. Now, a continuing community of agents was created: The city was speaking across what previously were voids of silence. The factory reform movement grew into a powerful force in support of the social responsibilities of government. That episode of urban ethics probably could not have occurred in agricultural America; the tragic conditions that ignited the response would not have existed in the first place. The concentration of concerns and energies, the organization of powerful forces, the explosive intensity of public emotion, and the perspicacity of political strategy all required the dynamics of the city.

So, I say in conclusion that urban bioethics can draw on all these elements of city life and view them under the moral perspective of social responsibility, in its Niebuhrian sense, of creating the personal, cultural, social, and economic environment in which persons can be responsible personally as they interpret actions upon themselves and creatively respond to them in an ongoing community of agents.

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