

AIDS AND THE COURTS

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CHAPTER 13

**TOWARDS JUST
SOCIAL RELATIONSHIPS
BETWEEN SOCIETY
AND PERSONS WITH AIDS**

Mark H. Moore

The issues posed by the AIDS epidemic are emotionally and ethically as well as intellectually challenging. Harold Jaffe gave a lucid account of the past, present, and likely future of the epidemic (see Chapter 2, Section 2.1). David Musto (Chapter 4) has explained the powerful social dynamics that come into play when a society confronts a frightening epidemic. Some of those responses are beneficial in controlling the epidemic and mitigating harm; others are quite dangerous and irrational.

The issues addressed here are issues of justice: namely, what does justice require society to do for persons with AIDS, and what may persons with AIDS justly be asked to do for society? More particularly, what concrete bundle of special rights and responsibilities associated with HIV/AIDS would constitute a just relationship between persons with AIDS and the rest of this society? The answer to that question can be satisfactory

and socially stable only if both sides agree to it. The answer should have a reciprocal quality.

Why is the issue of just relations an interesting one? First, as David Musto would tell us, the quality of social relationships and justice in this society is one of the most immediate and, perhaps, one of the longest lasting casualties of a frightening epidemic. As a result, if we're going to manage society's response to the epidemic carefully, we'll need to keep our eyes focused as closely on the development of these reciprocal rights and responsibilities as on the spread of disease and the economic costs of managing it. The greatest long-run damage to society might well lie in the loss of our sense of justice, rather than in the losses that will register in this society's health. As an important dimension of our response, then, we have to keep a keen eye on the nature, the quality, and the justice of the relationship that exists between society and persons with AIDS.

Second, working out the reciprocal rights and responsibilities of the society and persons with AIDS is one of the most important devices this society uses to manage the problem. It defines who has to carry the burdens of responding to the illness, and helps to organize the social work of responding to the illness. For example, one way to view the problem is that a tragedy has befallen society. People are sick, they're going to continue to be sick, and they're going to spread the illness. The policy and legal question is, what is society going to do to manage that set of problems and who, in particular, must do what kinds of work, and absorb what kinds of losses? As we work out who is responsible for what, we will produce the social mechanisms for controlling the illness and caring for the people who have been afflicted. Thus the first reason to be concerned about reciprocal relations is that it's an important relationship that will be affected by the disease and will be a mark of our distinction as a society in terms of how we handle it. The second is that it becomes an important operational device for helping this society manage the illness.

The third reason to be concerned about the justice of the relationship between society and persons with AIDS is that the construction of a tolerably just and effective set of reciprocal rights and responsibilities will signal the resolution of the problem. Where we get into trouble with these illnesses is at the extremes of non-response and response, when we're either indifferent to or denying the existence of the problem, or when we're fleeing in terror from it. We are making progress when we have worked out an understanding shared between the society and the persons with AIDS as to our reciprocal rights and responsibilities toward one another. For the above three reasons, then, it's important that society, and perhaps judges as people who are especially concerned with the quality of the relationships in this society, should think further about what reciprocal rights and responsibilities could be defined that would be

fair to persons with AIDS, aid them in bearing the terrible burdens of their illness, and also help to minimize the continuing health threat to the rest of this society.

I'm talking as if nobody had done any thinking about what the nature of those reciprocal rights and responsibilities should be. Of course, that isn't true. There is already in place a set of laws that implicitly define the reciprocal rights and responsibilities. At the moment, we tend to think about the nature of reciprocal rights and responsibilities in two different ways. One begins with a concern about the spread of the illness. The society faced by that fear begins thinking in terms of controlling the conduct of persons with AIDS by creating new liabilities for testing, for imprisonment, and for segregation. That's one picture of what's going on.

The other way is that those pressures for protecting society against the threat are held in check by defending the civil liberties of the people who now have the illness, and by making humanitarian appeals of various kinds for the care and protection of persons with AIDS. At the moment we see a struggle between public health objectives perhaps animated by some not very attractive social desires for rejection and control on the one hand, against the bulwarks that have been constructed to defend civil liberties and appeals made to our better instinct to care for the people who have AIDS on the other.

Why do we see things in those terms? Well, we're organized for seeing things this way. It is a familiar dialogue in our society. It's how our laws developed. We're aware of the threats of discrimination and prejudice, yet we're also aware of how compelling the claims of public health and safety can become against civil liberties. We cling to constitutional rights to privacy and to freedom for guidance as to where justice lies. With this as the backdrop for discussion, society then seems to divide itself along fairly predictable lines. Some argue for the crucial importance and the urgency of making new claims to protect the health of the broader society against those who are now seen to represent a threat, and offer nothing in terms of a sense of responsibility to the people who have the illness. Others, making the opposite argument, wish to defend, intact, the rights of the people who have the illness, to make additional claims for their care, and to refuse to acknowledge any new obligations that might be created for the persons with AIDS.

Those differences between the people who, on the one hand, are trying to protect the rights of persons with AIDS intact and assure that they have access to treatment and to non-discrimination, versus the people who are concerned about controlling their conduct to control the spread of the disease, those two different camps map on to two slightly different pictures of where the disease came from and whose fault it is. Those who are interested in defending the people with AIDS against any encroachments of their rights tend to think of the disease as something

that has befallen the community and that could have happened to any of us, and that therefore should create no new additional obligations and should be publicly managed. Those who believe it is most important to defend society against the threat are more inclined to see the illness as something that the people who have the illness brought on themselves and which now represents a threat to the society, for which, therefore, the people who have the illness might be asked to accept some of the responsibility for managing it.

Those are images of justice. They're images of what a *just response* to the problem of AIDS would be, as well as images of what an *effective response* to the problem would be. In my view, those images that are now contending are incomplete and imperfect; neither properly describes the conditions we find ourselves in nor prepares the society for making an adequate response to the epidemic. I'd like to propose an alternative way of thinking about just relations other than those two rather familiar contending alternatives.

The alternative way that I'd like to propose begins with an observation that there might be important differences in the social position or status of a person with AIDS from that of an ordinary citizen. Wisdom begins with an explicit acknowledgement that persons with AIDS are different. Their difference results in a somewhat different bundle of rights and responsibilities. To sense the difference, ask yourself how your status would change if you suddenly discovered today that you had AIDS. What would that mean for you as an individual? First, you probably would be filled with despair. You'd need the comfort, solace, and support of a large number of your fellow citizens. Second, you'd be looking ahead to a long illness that would be very expensive and would gradually bankrupt the resources of your family, and, perhaps, your insurance scheme. Third, you would face unpleasant questions about what kinds of responsibilities you had for containing the disease further.

Those are important differences in the conditions under which an AIDS victim is living from the conditions under which other people are living, and those different conditions demand social recognition. They demand social recognition because it is true that we will end up having to care for persons with AIDS. They're important because the observation that persons with AIDS are different entails the idea that we will have to defend them against discrimination. We will have to make sure that they have access to a regular community life against the fears and irrationalities of the rest of this society. The differences also mean that persons with AIDS have to accept additional responsibilities for guarding against the future spread of the illness. Implicit in this idea is the assumption that persons with AIDS, and perhaps even those at risk of having AIDS, are not quite the same as everybody else in this society. Their bundles of rights, responsibilities and privileges differ.

Persons with AIDS have some additional rights that they can claim against us for treatment and for protection against discrimination. They also may have some responsibilities that we can feel justified in imposing on them, specifically the obligation not to spread the disease further.

Obviously there's a great danger in establishing a difference in status and condition between everybody else and persons with AIDS. Indeed, it's important to keep in mind that they are the same as us, as well as different from us. They *are us* in many important senses. There is also the truth that persons with AIDS represent challenges to this society for care and for protection against discrimination, and that this needs to be acknowledged and addressed, and neither denied nor fled from in panic. That seems to me to be the core of the idea.

Notice that an important part of developing this idea is that persons with AIDS have both new rights against this society and also new responsibilities. In my view, rights and responsibilities can only justly change together. That is, if we are going to impose new rights or create new rights for persons with AIDS, we might be justified in creating new responsibilities. If we create new responsibilities without creating new rights, I think both the justice and the efficacy of our plan will be inappropriate. The argument that I'm making is that it's an important challenge for us to think concretely and specifically about what particular rights and responsibilities people with AIDS might have with respect to the rest of this society.

In thinking about that, I propose three different standards. The first standard: What might we owe to the most innocent victims of the AIDS epidemic? Now, what do we mean by an "innocent victim?" The most concrete picture of that is the people who get the disease through no fault of their own. These people would be hemophiliacs, children of persons with AIDS, and perhaps also homosexual and heterosexual men and women who got the disease before there was information about it, so there was no reasonable way they could have foreseen it and protected themselves against its hazards.

Notice that for that group of people who might be thought of as the most innocent victims, we're inclined to grant a relatively large number of rights and claims for them against the rest of this society, and to try to minimize the burdens, because it seems somehow unfair to impose burdens on people who through no fault of their own ended up getting the disease. Nonetheless, I think that if one thinks about that question for a time, even where the most innocent victims of the disease are concerned, we imagine that there might be some moral obligations, some notion of social responsibilities, that those victims would have to take on themselves to help society as a whole manage the epidemic. We hope that they would be willing to do that, particularly in a world in which we had extended a substantial number of rights to them. So even with the most innocent

victims there is a picture of the possibility of imposing moral obligations on people who have the illness, as well as vindicating rights that they have vis-a-vis the rest of this society.

The second standard of justice might be the one given to us by the philosopher John Rawls, who suggested when confronted with a question about justice, about what we owe to one another, that we ask ourselves the question of what we would agree to in a world in which we didn't know in advance where we would be in this society (in this case, whether or not we would be an AIDS victim). If you go through that process, you, perhaps like me, will come to the conclusion that I believe I would agree to a system that extended substantial rights to persons with AIDS for treatment and for protection against discrimination, and also one in which there would be a reasonable number of responsibilities and obligations created to help this society not spread the illness. That seems just in an important sense.

The third standard (I'm edging away now from the more innocent pictures of the world) would be a standard that acknowledged that there might be some individual responsibility for getting the disease, that having the disease might have been the result of individual choices made. Now, there's a version of this which is a deplorable version, and I don't want to confuse that with the one that I'm talking about. It is, of course, true that one of the worst things about the illness as it now appears in this society is that it appears among risk groups that are already heavily the objects of discrimination: homosexuals, IV drug users, people of color, the poor. They are already people who are discriminated against for a large number of other reasons.

It's not those things that make the victims of AIDS "guilty." Those would be completely inappropriate bases for deciding that more burden should be created than more rights established. What I think is a reasonable basis, though, for thinking about personal responsibility, is the extent to which people change their conduct and accept the responsibility both to try to avoid getting the disease, and to avoid spreading the disease. By this standard, in the future there will be fewer innocent victims of AIDS. The reason is that now we know about the problem. We're all learning about it and, as we learn about it, presumably we are all accepting responsibility for avoiding getting the disease and avoiding spreading it. That will leave only babies born with AIDS as innocent victims.

If the epidemic remains concentrated in the current risk groups, it will be very easy for this society at large to decide that the victims of AIDS are "guilty," to deny them rights that they should have, and to impose on them responsibilities that would be unjust. If, on the other hand, a great tragedy occurs, if the disease leaps into the general population, it will be easier for society to imagine that *we are they*, and

suddenly to discover the virtues of vindicating rights and imposing the smallest possible number of new obligations.

I point these things out to you to show that the epidemic is going to look very different, depending upon whether it stays in current risk groups or extends out. But in principle, that shouldn't be important. What should be important is that we are all gradually coming to understand that we will have some responsibilities for avoiding getting the disease, as well as avoiding spreading the disease. What I'm arguing for here is a position that says, "If you're a person with AIDS, you have some special rights against this society which this society is determined to vindicate, and some special responsibilities which this society is also determined to establish and see that you live up to."

What would that mean for some concrete questions? How about the availability of testing? If you take this point of view, the availability of testing becomes crucially important. There ought to be a lot of it available. It ought to be accurate and high quality, so that people can find out what their status is and therefore what their rights and responsibilities are. I believe that it also suggests that testing should be widely encouraged; that if it's true that being a person with AIDS changes your status, then people ought to know whether they're in that status or not, and we all ought to have the courage to face up to that.

Incidentally, I believe that developing the courage to face up to that will be aided by a conclusion that says that, if you discover that you are a victim of AIDS, you will have special access to rights and you will not be the victim of discrimination, and society pledges itself to that goal. That seems to me to be very important, and that the burdens imposed on you will be very minor.

If we could get that deal, then the possibility and the consequences of testing look very different in a world in which this society has already figured out what justice requires with respect to AIDS patients, than in a world where we are still contending with one another about these questions.

What does it suggest about what we should do about irrational discrimination? The answer is that we should fight it every time we see it. The public should commit itself to such a fight, expanding the set of possibilities for persons with AIDS to participate fully in the life of the community.

What does it suggest about treatment? My view is that this society should assume the responsibility for paying for treatment. I think that we ought to view AIDS as a tragedy that's befallen the community, not something that has happened to any particular individual, although, as I mentioned, that will become less and less true over time. I think it's inevitable that this society will end up paying the bill for treatment anyway. We might as well decide up front that this is what we're going to do, and

then create the climate within which the proper relationship between this society and persons with AIDS can emerge, instead of a world in which everyone is trying to fob off the individual with AIDS onto somebody else's budget so that they don't have to pay the price.

Note the crucial importance of linking the creation of new rights with new responsibilities. I believe that the creation of rights without responsibilities for persons with AIDS will not succeed in this society. I further believe that the creation of responsibilities without rights for persons with AIDS will also not succeed. It will not succeed as an image of justice, and it will not succeed as a device for controlling the future threat of the illness.

What is my conclusion? It's this: Developing a clear conception of the reciprocal relationship of the contract between persons with AIDS and the broader society is crucial to the society's future success in managing the epidemic. By deciding on what that will be, it facilitates the crucial move that must be made in this society toward the normalization of relationships, beyond the alternating periods of denial and panic that are some of the features of this society's current response to the problem. If we develop a conception of what the reciprocal relationship should be, it answers a great many of the more specific policy questions. Moreover, by answering them all at once, you get a different answer than you do if you develop an answer to them on a piecemeal basis. This notion of reciprocal relations is cast in a language of fairness and justice that ordinary people in the United States can understand. It's true to the facts of the predicament in which we now find ourselves, and perhaps it's a way of thinking about the problem as we sort our way and try to find our path of this society's adaptation to the problem. Those concerned with justice and with the judges themselves might find it particularly amenable. It might be a kind of language for judges to use as they talk to communities about what justice requires in this society's response to the AIDS problem.

CHAPTER 14

FAMILY LAW, DIVORCE, AND AIDS

14.1 IS AIDS GROUNDS FOR DIVORCE OR LOSS OF CHILD CUSTODY?

Kristin Booth Glen

My expertise is more as a professor of family law than as a judge. Not that I haven't seen some cases involving AIDS and family law and domestic relations, because a large population of people in Manhattan is infected with HIV. But none of us see cases of people infected with HIV across the entire spectrum of family law. One may see two or three cases over the course of a year or two, but not in all areas.

The issue of domestic relations is perhaps the area that is most reserved to the states and where the differences among the states are possibly greater than anywhere else in the law. Understanding that, as each of us hears or determines cases involving family law, we must do so within the context of our own body of case and statutory law which may be quite