Volume 34 | Issue 5 Article 8

1989

Symposium Proceedings

Various Editors

SYMPOSIUM PROCEEDINGS

Following the presentation of the papers by the symposium participants, the speakers addressed questions posed by various audience members. The inquires made and responses given are printed below.

Audience Member (to Professor Turkington and Mr. Burris): I have the impression that you view the federal government as the sole source of a response to AIDS and that the federal courts and Congress are the fonts of rationality. What about claims in the state courts? Can't arguments based on state constitutions, which often provide greater protection than does the United States Constitution, or on state legislative alternatives that are being developed to cope with this crisis be made?

Professor Turkington: I hope that I did not leave the impression that I thought that the federal government was the fountain of wisdom. You raise a very good question. There is a tendency in the confidentiality area for state courts to take the lead in protecting rights and to be more sympathetic to constitutional privacy and informational privacy arguments than before. I think this is because of the powerful arguments linking AIDS and privacy and the risks of disclosing AIDS-related information. The Wisconsin case of *Woods v. White*[1] goes beyond Supreme Court precedent in holding that disclosure by the government of intimate information might violate the constitutional right of privacy. The Supreme Court case, *Whalen v. Roe*,[2] merely suggests that and is dicta. Poor legislation can to some extent be corrected by the courts' finding it unconstitutional. Thus, the constitutional developments do provide some check on policies that are wrongheaded. However, I would not want to bring the question of whether the disclosure of HIV- or AIDS-related information violated a person's constitutional right of informational privacy before the current Supreme Court. I cannot see the Rehnquist Court expanding constitutional informational privacy rights. Nevertheless, as you point out, there are several state courts that interpret their state constitutions in such a way as to give greater informational privacy rights. These state courts would be quite sympathetic to such a privacy argument given the right case. Ex-

1. 689 F. Supp. 874 (W.D. Wis. 1988).
2. 429 U.S. 589 (1977).

amples of such state courts include those of Pennsylvania, New York, New Jersey and California and maybe a couple of others. State constitutional development, at least in some states, may provide a balance against wrong-headed legislation to protect informational privacy rights.

Mr. Burris: I would like to comment to that a certain degree. The Rehabilitation Act and the decisions surrounding it are a fountain of rationality in that they encourage people to try and fit their claims into the Act and decisions construing it. Speed is also a factor. There is very limited time in which a person with AIDS or HIV is interested or able to pursue litigation and federal courts are swifter.

Ms. Dunlap: I would not say that either the federal or the state governments should be expected to be a font of rationality. The purpose of my presentation was to make the point that the opposite has too often been the case. As for the California state courts taking on questions of constitutional privacy, California's constitution guarantees privacy on its face, interestingly enough, by means of a voter initiative fifteen years ago that adopted a constitutional amendment. I am not even a little bit sanguine about the prospects of surviving *this* court's review. The California Supreme Court was the subject of a right-wing attack which resulted in the removal of Rose Bird and President George Bush promises not to appoint anyone like Rose Bird to the federal courts, so I guess we are gone.

Audience Member (to Ms. Dunlap): How have employers reacted to the fear of a Title VII suit versus fellow employee paranoia? Have they just decided to fire the employees?

Ms. Dunlap: There have been a number of cases involving employee terminations. The San Francisco Human Rights Commission, for example, has documented some several hundred cases where people believe they have been dismissed from their employment because of AIDS, ARC, HIV infection or fear in a first amendment sense because of their association with people with AIDS. Employers vary dramatically in their policies. We have models in San Francisco, such as Levi Strauss, which have done a magnificent job nationally in educating employers about the importance of not overreacting. At the other extreme, we have employers who have openly fired people and taken their chances. Very few of those cases make it to court because there are problems of resources and of priorities. If I were in the last years of my life, one of the last things I would choose to do would

be to litigate. Keep in mind that when you are thinking about people enforcing existing rights, extending rights to new contexts or developing rights, many people with AIDS and ARC do not find it a particularly desirable choice to fight these battles. Questions of doctrinal standing and the like get in the way of the development of consistent principles. The employment cases are generally optimistic, as I said, but with a caveat that this underlying wave or current of irrationality—well, we called it irrationality, but it may be something worse—may overwhelm any possible optimism.

For that matter, I don't think reason is the total answer. The Quilt is the answer. The Quilt is more than reason; it is connectedness; it is grassroots organizing; it is a whole variety of things. Some employers have taken all that into account.

Audience Member (to Professor Annas): Assuming that eventually there will be an effective vaccine or some kind of technological fix, what lasting changes or overall historical significance do you see in the current response to the AIDS epidemic?

Professor Annas: First, just let me comment on the "technological fix." The NIH, C. Everett Koop and every other knowledgeable scientist in the world do not expect a vaccine before the year 2000 at the very earliest. Thus, we are looking *way* into the future. Then, it would probably take another ten years to test that vaccine. So, don't expect a vaccine. Treatment drugs? Maybe, but Commissioner Young, who is the most energetic and optimistic person, does not see more than one or two drugs that are even a little bit better than AZT being available before the year 1991. Of course, we hope that there is going to be some technological fix, but it won't be soon.

Mr. Burris: As far as changes go, I think a lot of that depends on our response to AIDS. It is very easy for society to continue to discriminate. This is a society that has fundamental changes every couple of years, and consequently I discount about ninety-nine percent of the analysis I hear of our "great" social changes. Nevertheless, you raised a point that is worth making. It depends on who this disease hits. If AIDS remains the disease of gay people and poor people and we as a society just let it happen and become part of the impression about gay people and part of the business as usual of the third world health conditions in the ghetto, then AIDS won't change us for the better. It may tend to make us more like oligarchists in Central America, detached from social reality and cut off from the pain and suffering of a full seg-

ment of the population. However, I do not see changes ahead in the sense of people really saying, "Well, my sexual practices have got to change." I do not see changes in the sense of people saying, "This disease shows us how unfair this society is." But AIDS does show us how unfair society is. It shows how many people are deprived of the basic necessities of life. The problem is that AIDS is not really doing enough.

Professor Furrow: There are a couple of historical examples that are interesting. The history of tuberculosis in the United States from 1900-1910 is one such example. New Mexico had had on its books for a long time a statute that empowered a public health officer to arrest someone who was suspected to be a T.B. carrier. That statute goes back to the days before tuberculosis could be treated. There is also a very nasty tradition in tort law that dates back to that same period involving use of public nuisance law to keep sanitaria out of the suburbs. This is advanced zoning as in *Euclid*.[3] Tort law was used to do effectively what people want to do today through zoning or through referenda to keep suspect and contagious groups out of their community. There is history and there is precedent that suggests that we have been nasty in the past. However, this is worse.

Ms. Dunlap: Let me offer that Michael Callen, a person with AIDS, AIDS activist and musician, has said: "AIDS is a cosmic kick in the ass." I love that for its ability to describe some of the ways in which AIDS magnifies both existing problems and areas of change. Among the ones I note in my article are that: the legal system is too often punitive rather than educational, decent medical care costs more money than most people have; the debate on national health insurance *certainly* is being conducted in the light of the proposition that AIDS affects and will continue to affect a great number of people; the average cost of AIDS health care is estimated at somewhere between just less than $30,000 up to $120,000 per person over the life of the disease. This is a very important area of change which once again the Quilt embodies; the nation suffers from a massive denial of the realities of illness and death.

In reference to Dr. Annas's remarks about the whales,[4] while

3. Village of Euclid v. Ambler Realty Co., 272 U.S. 365 (1926).

4. Dr. Annas began his presentation with the following remarks to which Ms. Dunlap was responding.

> The topic that I am going to address is "The Regulation of AIDS Drugs," but it has a subtitle. This subtitle has developed over the last year as I have been thinking about this topic and seen it as a moving

I don't necessarily agree with him, I would save the whales before I would save the FDA. In fairness to Dr. Annas, AIDS is illuminating the key point that we are in deep, tragic denial about the nature of death itself and we look for technological fixes against our own mortality.

Finally, my major point was that AIDS has the capacity to teach those of us who work in the legal system to overcome our own bigotry. It also has the capacity to enable us to embed that bigotry even further in our values. AIDS has both potentials. I don't mean to sound too Buddhist about this, but we see both capacities in our reactions to this epidemic.

Professor Furrow: If I may make one magnifying point building on that metaphor. There was a recent study that ranked the United States as compared to eleven other countries, European, and Turkey and Greece, in terms of the proportion of our gross national product we spend on health care generally and in terms of the amount of our health care expenditures that we spend on public health-defined health care. The United States ranks first, or worst, on the proportion of money in GNP we spend on health

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target. As you read in the *New York Times* and other papers almost daily now, the FDA changes its rules. The subtitle of this presentation is "Rescue Fantasy at the FDA." I will focus on how the AIDS epidemic tests our notions of what is safe and effective in drugs and on what regulatory agencies should do in response to this very difficult issue.

I want to begin with a drama that the whole world is watching which is the three whales that are trapped beneath the ice cap in Alaska, although I understand that this morning there are only two survivors. It has been one of those rare dramas that has brought the world together in a sense of the electronic global village, to witness and to hope and to try to help these trapped creatures. The question has to be asked: Why? Why do we care about these three whales? There have been a lot of suggestions about that in the last week, and it seems to me the reasons are two. The primary reason is because we fear death and we do not want to see creatures die because it reminds us of our mortality. Secondly, we believe as a society, if not individually, that our technology can avert death; that our technology is strong enough and powerful enough to save creatures from death and therefore to save ourselves from death. We see this as an affirmation of the ability of technology to save ourselves and the whales from death, and that is why we put our technology to the test in Alaska.

Whether it fails or not is not the point. The point is that we do this for a purpose: to reinforce our belief in life and our belief in technology as life preserving. I suggest to you that that is a rescue fantasy. That is a fantasy for us to believe—that the whales can live forever, that we can live forever. It is a fantasy for us to believe that our technology can solve all of our problems. That is exactly the problem we confront with the AIDS epidemic. We are confronted for the first time in modern history with an epidemic, a disease that we are powerless to deal with in terms of technology, in terms of drugs.

care. That is, the U.S. spends the most, and that is compared to Norway and Sweden, countries with socialized medicine. The United States ranks last in the proportion of health care expenditures we spend on public health, and that is compared to Turkey, for example. Now it seems to me, that the AIDS epidemic may magnify that particular kind of imbalance we have in the American political system.

Audience Member (to Professor Annas): Part of your argument for advocating a strong FDA and the preservation of experimental and regulatory controls is a limit on the profusion of quackery in AIDS treatments which is a variant of a "save the people from themselves" argument. I wonder why you advocate this approach in the area of AIDS drugs when, for instance, we do not take that approach in many other areas; we allow people to use carcinogenic tobacco products with little limitation. You mentioned that part of the reason for doing this was the utility of preserving scientific soundness and a harmonization of AIDS drug trials with other drug policies in this society. Isn't this essentially a social utility argument?

Professor Annas: I advocate scientific soundness for all drugs, not just AIDS drugs. The concern is that AIDS drugs will drive all of the other drugs down to their level, rather than AIDS drugs being the exception. That is what happens. That is what the drug companies want. Essentially, the drug companies have wanted two things for years. First, they want to be able to charge money for experimental drugs, and they are doing that now with the so-called treatment INDs, or investigational new drugs. Second, they want Congress to pass a statute limiting their liability in products liability drug suits. The drug companies do not have that yet, but it is the next step considering the President's AIDS Commission report. The report points out that the main reason treatment INDs have not been used by drug companies is that they are worried about their potential liability. The Commission did not recommend to Congress that it pass such a statute, but the drug companies will lobby for it.

Indeed, I would argue the same thing as C. Everett Koop recommended strongly in the *New York Times* on October 22, 1988, and as many other health officials do, that the FDA designate the new smokeless cigarette "Premier" as a drug or at least as a drug device. Commissioner Young has said that he would like to do that, but the only reason he might not be able to do so is because all of his staff is currently working on AIDS. The FDA might just

be swamped with R.J. Reynolds trying to fight that. The FDA cannot do its job for other drugs. The FDA cannot do its job to protect the public health. We have 300,000 people who die each year of illnesses related to cigarettes.

I am not saying that AIDS is not a problem, but we have other problems too. If we let AIDS drive out all other health and drug problems, we have got major problems. If you listen carefully to what Mr. Burris said, I think he is absolutely right that the United States Supreme Court is finally starting to listen to scientific rationality and reasoning. That is what he wants the Court to do, and so do I. Nevertheless, it is difficult to argue to the Court that when we talk about prejudice and fear, it should listen to science and be rational on the one hand, and on the other hand, when I want my drugs, forget science and rationality. Just give me what I want.

Audience Member (to Professor Turkington): For years and years, workers in manufacturing industries have dogged their employers to find out what carcinogenic or toxic substances they were being exposed to in the workplace. Manufacturers protected themselves by saying that they could not release that information because to do so would force them to disclose trade secrets and violate their property rights. But nonetheless, the workers eventually got past the manufacturers' maneuvering with the Right to Know Act. Can you draw a distinction between the right of a chemical worker, for instance, to know what they are being exposed to in the workplace with a spouse's right to know if their husband or wife has AIDS?

Professor Turkington: That is a very good question. I certainly can draw a distinction between an employer's right to know about HIV- or AIDS-related information in respect to employees or fellow employees' right to know about HIV- or AIDS-related information in respect to other employees and an employee's right to know about conditions which in a meaningful way threaten her life.

The question of informing the spouse, I think, is one of the most difficult in the area of confidentiality. I have come around reluctantly—although I may change my view—to the position that the New York statutes which I summarized in my presentation are probably a good accommodation of the interest in protecting the spouse from the risk of infection and the interest in privacy and protecting the integrity of the professional-client relationship. It is not as easy on the surface as it seems to be because, first, the

medical profession, or at least some members of the medical profession, takes the view that the responsibility ought to lie primarily with the health department to perform the police function. Second, the law is very unclear as to what the duty is or whether there is liability if you do disclose the information. If you do not disclose, *Tarasoff*[5] is not controlling precedent in that there are significant differences between the two situations. One difference is that in the *Tarasoff* situation, the patient is in no position to inform the endangered party of the problem, whereas with AIDS, the patient may be the right person to inform and discuss with the spouse or significant other the fact of infection.

It is a very difficult question, and the New York statute reflects a fair accommodation of the conflicting values. In circumstances as prescribed under the New York statutes, a physician who chooses to disclose ought to be able to do so and should be protected against civil liability. The question is whether the health department has an obligation, as it does with other contagious diseases, to try to locate past and present sexual partners who might be at risk.

Audience Member (to Professor Annas): Given that the success of a randomized double blind placebo trial is going to be dependent on the willingness of participants to obey the guidelines of the trial, where would you put in a legal context those trial participants who take their drugs to a pharmacist to have them analyzed to determine whether they are in fact drug or placebo after which the participants make their decision about compliance? Where would you put those doctors who conduct their own small scale nonrandomized trials of alternative therapies, and there are many of these being conducted in New York, San Francisco and Los Angeles? Do you anticipate any legal sanctions against either these patients or physicians?

Professor Annas: No, I don't. I do not think we will learn anything from those studies unfortunately. Those patients may be found out when we get bad data on the basis of the randomized clinical trials. Of the doctors who are doing the small scale trials, most of them are performing the trials because there are no other studies that those patients qualify for, and the patients really want to be in studies. I have nothing against that. That is fine although, unless very careful data are taken, it is unlikely that anything will be learned from them. You may learn something from

5. Tarasoff v. Regents of the University of California, 17 Cal. 3d 425, 551 P.2d 334, 131 Cal. Rptr. 14 (1976).

these small studies. You are never going to learn anything from experiments individuals do on themselves by mail ordering drugs from other countries and administering them to themselves. The small studies have some possibility, but not much. The odds are so great that you are not going to learn anything that way that it is almost a waste of time. I am not saying it is totally a waste of time.

Dr. Fauci has said, for example, that the NIH is going to be testing 10,000 different compounds in 1989 and every year from now on—10,000 compounds a year *in vitro*, in the test tube, that it has on the shelves against the AIDS virus. He does not expect to find anything that works there, but, nonetheless, he is going to do it. David Baltimore, from MIT, thinks we need a whole new approach; we need a whole new science of virology to do this. We are much more likely to learn of a new approach, not by testing things that are already out there, but by developing a new antiviral technique which will require some new insights. There are eighteen working groups around the country trying to do that. It is very frustrating for people. I am not arguing that it is not frustrating for people who have AIDS, cancer or other diseases. What I am arguing is that, as cruel as it sounds, it is probably better for these people to start coming to terms with their diseases and their death, than it is for them to go running around for what are basically quack remedies.

Audience Member (to Professor Annas): It sounds like you are saying that you feel that these individuals should be involuntarily relegated to the status of the experimental control. In other words, if they cannot have drugs of their own choosing, they are, in effect, being the population controls for the natural history of the disease, whether they want to be or not.

Professor Annas: No one can have drugs of their own choosing. That is the question: Do we want to eliminate the drug laws or not? I do not, but I can understand those who do. That is absolutely the question. The real issue is not, as Judge John Marshall tried to frame it in the Dallas Gay Alliance suit against Parkland Memorial Hospital.[6] Judge Marshall said: "Well, this court is going to require Parkland Hospital to give aerosolized Pentamidine," which actually is a fine drug, but was not approved at the time for patients, "because we are not going to sit by and

6. Dallas Gay Alliance v. Dallas County Hosp. Dist., No. 88-6346-A (Tex. Dist. Ct. 1988), *removed & appeal docketed*, Civ. Action No. 88-1394-H, (N.D. Tex. 1988).

let these patients die." The truth is that patients are going to die, and whether the court sits by or does not sit by is not the relevant issue. This again is fantastical, magical thinking. It is a rescue fantasy that we can save these people by giving them drugs that do not work. The only way ultimately to rescue these people is to develop drugs that do work, and the only way to do that is to conduct randomized clinical trials.

Ms. Dunlap: I would like to offer a somewhat different view in response to that question. It seems to me, in a way, that all of our ideas are played out into a dichotomy, and I do not like to see myself on the side on which I am finding myself which is in favor of "scientific rationality."

I refer to the *Village Voice*, February 16, 1988. Women have not been among the Ampligen subjects—Ampligen is a leading AIDS-related drug that may be very important in prolonging life among other things . . .

Professor Annas: That is disputed.

Ms. Dunlap: . . . but here is the reaction of Dr. Michael Greco of St. Luke's Ampligen Program when accused of discriminating against women: "Women are not part of five out of thirteen of the trials going on right now. The best patients have been male homosexuals. Woman," I think he means women, "have less compliance. There is less education, motivation and understanding. It is different taking someone who is productive in the arts than living as a minority person. They are not going to have the same grasp." Let me suggest that everything we wrap in the wrappings of science may not be science. Everything we wrap in the wrappings of politics may not be politics. It is extremely important for all of us to take a much closer look at people's underlying value systems when they are offering these models as scientific or political or whatever they may be.

Professor Annas: Of course Dr. Greco's statement was a stupid statement, if he made that statement.

Ms. Dunlap: Five drugs out of thirteen are not being tested on women. Stupid or not, that is a scientific reality.

Professor Annas: The reality is and the reason they do not test women is because they are afraid they are teratogens. There are ways to get around that. You are correct, women are not being adequately tested, nor are intravenous drug users. I am not sure that that is a deplorable thing necessarily. They are not getting any kind of medical care. First, we want to get basic medical

care to everyone, then we can worry about experimentals medical care.

Dr. Forrester: I would like to add as a health researcher that I do subscribe to the scientific method and that I do support the idea of the clinical trial. Yet, our patients are endlessly creative and resourceful whether they are women or men. It is my experience that the scientific method goes out the window when our patients go outside the clinic and trade their drugs. I don't worry about them too much. Everyone is getting AZT. That is why many of the AZT trials were abandoned; the patients were confounding them in an effort to get a drug that they perceived could help.