

Law and Empowerment: The Idea of Order in the Time of AIDS

H. Dalton,* S. Burris,** and Yale AIDS Law Project, *Editors*. *New Haven, London: Yale University Press*, 1987. Pp. xi, 382. \$7.95.

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AIDS is about . . . loss of control—control of one's bowels and bladder, one's arms or legs, one's life . . . AIDS is the moment to moment management of uncertainty. It's a roller coaster ride without a seat belt. Once this ride begins, there is never a moment when the rush of events that swirl around you stops long enough for you to get your bearings. AIDS is like motion sickness except you realize that you'll never stop moving; one way or another, you'll be dealing with AIDS for the rest of your life. . . . It's like standing in the middle of the New York Stock exchange at midday: buzzers and lights flashing, everyone yelling, a million opinions, a momentum.

— Michael Callen, *Person With AIDS*††

As a gay man, I experience the AIDS crisis as the triumph of anxiety and uncertainty. Am I infected with a deadly virus? Are my friends? If we are, will we die? How horribly? How soon?

Every aspect of the AIDS crisis resonates with this uncertainty. Scientists still debate whether the human immunodeficiency virus (HIV) is the "cause" of AIDS. They are unable to explain why the virus can lay dormant and harmless for years and why it is then suddenly activated. Nor can scientists explain the differing physical manifestations of HIV infection or predict what infections will afflict which of us, when, or how. Our doctors (for those of us who have doctors) are unable to provide treat-

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†† Callen, Remarks at the Annual Meeting of the American Public Health Association, Las Vegas, Nevada, 1986, *reprinted in* SURVIVING AND THRIVING WITH AIDS: HINTS FOR THE NEWLY DIAGNOSED 39 (M. Callen ed. 1987).

ments and we have only limited success gaining access to "experimental" drugs, which then have little success in our bodies. Society's primary response is concern that AIDS will "break out into the general population," of which, presumably, we are not a part, and where, presumably, the deaths will really matter. Society threatens us with quarantine, barely veiling its contempt and hatred, while promising, but rarely delivering, compassion.

"Now for the good news," writes editor Harlon Dalton in his preface to *AIDS and the Law: A Guide for the Public*: "In putting together this book I have become convinced (much to my surprise) that our legal system is uniquely suited to the task at hand."¹ Dalton's "optimism"² springs from the fact that "[t]he law's formulaic quality means, among other things, that we need not reinvent the wheel to deal with AIDS-related legal issues. . . . The practical differences . . . can be apprehended and taken account of by the law with relative ease."³

AIDS and the Law is a herculean effort aimed at describing the legal aspects of the AIDS crisis to the public. The book, a collection of twenty essays, each written by different authors, arranges the AIDS crisis into six sections: Medical Background, Government Responses to AIDS, Private Sector Responses to AIDS, AIDS and Health Care, AIDS in Institutions (the Military and Prisons), and the Problems of Special Groups (intravenous drug abusers, blacks, and the lesbian and gay communities). The collection is introduced by a preface from Dalton, an associate professor at Yale Law School, and by a chapter entitled "A Little Law for Non-Lawyers," written by the book's other editor Scott Burris, a recent graduate of Yale Law School.

Inherent in an effort like *AIDS and the Law* is an attempt to order the uncertainty and to control the anxiety that defines the AIDS crisis. At times this organizing effort is explicit, as in Dalton's preface; at other times it is more subtle. For example, existing laws are described as if they will automatically determine the outcome of AIDS-related litigation, while destabilizing developments, such as new laws, are submerged. Despite its "organizing" impulse, *AIDS and the Law* also captures the indeterminacy and contradiction of AIDS and the legal system.⁴ Litigative outcomes are described as unpredictable and the destabilizing consequences of changing laws are acknowledged.

1. Dalton, *Preface*, in *AIDS AND THE LAW* xiii (H. Dalton, S. Burris, & Yale AIDS Law Project eds. 1987).

2. *Id.*

3. *Id.*

4. These concepts are borrowed from David Trubek's summary of the critical legal studies (CLS) movement, arguing that the CLS critique of legal order "challenges the idea that a legal order exists in any society. The critique is based on four principles: indeterminacy, antiformalism, contradiction, and marginality." Trubek, *Where the Action Is: Critical Legal Studies and Empiricism*, 36 *STAN. L. REV.* 575, 577-78 (1984).

This essay explores the manner in which *AIDS and the Law* struggles to order the uncertainty of AIDS-related law. The first section focuses on AIDS-related litigation; the second section on AIDS-related legislation. My point in these sections is that one of the many values⁵ of *AIDS and the Law* is the manner in which the tension between order and uncertainty is reflected and played out in the book. In the third section, I discuss a parallel attempt to find order in and to control the AIDS crisis—the efforts of people with AIDS to overcome victimization and to take control of their lives. “We must fight,” Michael Callen writes, “to retain as much control over our lives as possible.”⁶ The fourth section is an example of the way these two efforts to control AIDS (the legal system and the AIDS empowerment movement) intersect. By drawing an analogy between these efforts, I attempt to demonstrate that another value of *AIDS and the Law* is that the book’s struggle to “organize” and “control” AIDS law coincides with the struggle of people with AIDS to “order” and “control” AIDS itself.

I. THE UNCERTAINTY OF AIDS-RELATED LITIGATION

Much of what constitutes AIDS law, and thus *AIDS and the Law*, is constructed from existing law.⁷ The chapters of *AIDS and the Law* discuss how AIDS will be incorporated into a wide range of traditional legal fields, from public health and criminal law to torts, labor, landlord/tenant, and insurance law. *AIDS and the Law* is essentially a march through these legal subjects, showing how analogous precedents have been, or might be, applied to AIDS-related situations.

At times, *AIDS and the Law* depicts these applications as “formulaic” and their outcomes as, therefore, inevitable.⁸ For instance, Dalton explains:

The law’s formulaic quality means, among other things, that we need not reinvent the wheel to deal with AIDS-related legal issues. As chapter after chapter makes clear, the institutional and concep-

5. The more practical values of the book to lawyers—for example, its helpfulness as a tool in planning litigative and legislative strategies—are lauded time and again throughout this essay. They cannot be overstated.

In addition, though I feel unqualified to comment on whether *AIDS and the Law* succeeds in its attempt to explain AIDS law to non-lawyers, the book’s editors should be highly commended for their effort. The authors of the book were chosen and the text carefully edited so as to make the book intelligible to non-lawyers. While much has been written for lawyers about AIDS law, *AIDS and the Law* represents the only such endeavor directed to non-lawyers. Finally, Professor Dalton, editor Burris, and the Yale AIDS Law Project deserve significant praise for having concentrated on the legal issues the AIDS crisis raises at a time when little attention was paid to such issues.

6. Callen, *Introduction*, in *SURVIVING AND THRIVING WITH AIDS: HINTS FOR THE NEWLY DIAGNOSED* ix (M. Callen ed. 1987).

7. The vast exception to that general principle is “new” law, namely statutes that have been passed by state legislatures and Congress to directly address the AIDS crisis. *See infra* Part II.

8. *See supra* note 3 and accompanying text.

tual framework for dealing with such issues already exists; the principles and procedures that will guide decision-making are, for the most part, already in place. Analogous situations abound, from cases involving sexual transmission of genital herpes to attempts to quarantine persons with bubonic plague; from cases involving schoolchildren infected with the hepatitis B virus to efforts to round up prostitutes to stem the spread of syphilis. Perhaps the most important guiding light is the explosion of statutes and cases addressing discrimination against the disabled and against people who are perceived as disabled.⁹

Although Dalton is correct that "analogous situations abound," what *AIDS and the Law* also depicts is not the "ease" with which AIDS can be "taken account of" by the legal system, but rather how indeterminate the applications of existing areas of law may be to this new situation.

A. *The Indeterminacy of Existing Law*

Consider, for example, Dalton's "most important guiding light,"¹⁰—"the explosion of statutes and cases addressing discrimination against the disabled."¹¹ Much of what constitutes AIDS law is built around the protections granted by section 504 of the Vocational Rehabilitation Act of 1973,¹² which considers people with AIDS to be disabled persons. For instance, as *AIDS and the Law* makes clear, HIV-infected schoolchildren and employees have successfully challenged their removal from the classroom and workplace by invoking section 504.¹³ But the very applicability of section 504 to AIDS (not to mention how cases would be decided) remained largely uncertain until a 1987 Supreme Court decision, *School Board of Nassau County v. Arline*,¹⁴ involving a tubercular school

9. Dalton, *supra* note 1, at xiii.

10. *Id.*

11. *Id.*

12. 29 U.S.C. § 794 (1973).

In relevant part, the statute provides:

No otherwise qualified individual with handicaps in the United States, as defined in section 706(8) of this title, shall, solely by reason of his handicap, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance or under any program or activity conducted by any Executive agency or by the United States Postal Service.

13. See, e.g., *Ray v. School Dist. of DeSoto County*, 666 F. Supp. 1524 (M.D. Fla. 1987) (school board ordered to admit HIV-infected schoolchildren to classroom); *Chalk v. United States Dist. Court*, 840 F.2d 701 (9th Cir. 1988) (school ordered to reinstate HIV-infected teacher to classroom duty).

14. 107 S. Ct. 1123 (1987). The uncertainty surrounding § 504's applicability was fostered in large part by the Reagan Administration Justice Department. In 1986, the Justice Department took the position that, although the Rehabilitation Act prohibited discrimination based on the disabling effects of AIDS, discrimination based on an employer's fear of contagion was not covered and therefore such fear could justify an employee's dismissal. The Supreme Court's decision in *Arline* specifically repudiated the Justice Department's position, stating "[w]e do not agree with petitioners that, in defining a handicapped individual under § 504, the contagious effects of a disease can be meaningfully distinguished from the disease's physical effects on a claimant in a case such as this." *Id.* at

teacher,¹⁵ held that persons with contagious diseases could be considered "handicapped" within the meaning of the Act.

Arline stands for the proposition that section 504 protects persons with AIDS. Yet, open questions concerning disability law still abound: are asymptomatic HIV-infected persons¹⁶ "disabled" within the meaning of section 504?¹⁷ Is an HIV-infected person not "otherwise qualified" solely

1128.

Nonetheless, not until it was prompted by the President's AIDS Commission some fifteen months later, see THE PRESIDENTIAL COMMISSION ON THE HUMAN IMMUNODEFICIENCY VIRUS EPIDEMIC, REPORT 121-23 (June 1988), and then ordered by the White House did the Justice Department retreat from this earlier position. U.S. Department of Justice, Memorandum for Arthur B. Culvahouse, Jr., Counsel to the President, Re: Application of § 504 of the Rehabilitation Act to HIV-infected Individuals 1 (Sept. 27, 1988) [hereinafter 1988 Justice Department Memorandum], Cover Letter from Douglas W. Kmiec, Acting Assistant Attorney General, Office of Legal Counsel (Oct. 6, 1988).

15. *Arline*, 107 S. Ct. 1123 (1987).

16. Asymptomatic HIV-infected persons are person who test positive for the presence of antibodies to HIV but who have developed no clinical manifestations resulting from their HIV-infection. Asymptomatic infection was traditionally considered the early phase of HIV disease, with the intermediate phase being AIDS related complex (ARC), and the final phase being acquired immune deficiency syndrome, or AIDS. ARC, as defined by the Centers for Disease Control (CDC), was the presence, for three or more months, of two of a list of clinical manifestations of disease (fever, weight loss, lymphadenopathy (swollen lymph nodes), diarrhea, fatigue or night sweats) coupled with certain specific types of poor blood counts, and the absence of the opportunistic infections which delineate the onset of AIDS. AIDS, the final breakdown of the immune system, was defined by the CDC as the presence of certain specific opportunistic infections which a person with a healthy immune system easily fights off. In particular, most people with AIDS fall prey to a pneumonia called pneumocystis carinii pneumonia, or to a cancer entitled Kaposi's sarcoma. These groupings are very well described by Richard Green in *AIDS and the Law*. Green, *The Transmission of AIDS*, in *AIDS AND THE LAW* 28, 30 (H. Dalton, S. Burris & Yale AIDS Law Project eds. 1987) (citing *Revisions of the Case Definition of Acquired Immunodeficiency Syndrome for National Reporting*, 34 MMWR 373, 373-375 (1985)). Because these categories are clinically inexact and definitionally clumsy, efforts have been undertaken to redefine AIDS as "HIV disease" and to refer to a spectrum of HIV disease, instead of to asymptomatic HIV-infection, ARC and AIDS. See, e.g., INSTITUTE OF MEDICINE, NATIONAL ACADEMY OF SCIENCES, *CONFRONTING AIDS* 7 (1986); INSTITUTE OF MEDICINE, NATIONAL ACADEMY OF SCIENCES, *CONFRONTING AIDS: UPDATE 1988* at 3 (1988); THE PRESIDENTIAL COMMISSION ON THE HUMAN IMMUNODEFICIENCY VIRUS EPIDEMIC REPORT 3 (June 1988).

17. The generally applicable definition of "handicap" in federal disability law is "any person who (i) has a physical or mental impairment which substantially limits one or more of such person's major life activities, (ii) has a record of such impairment, or (iii) is regarded as having such impairment." 29 U.S.C. § 706(8)(B) (1973). Physical impairment is then defined as, "[A]ny physiological disorder or condition, cosmetic disfigurement, or anatomical loss affecting one or more of the following body systems: neurological; musculoskeletal; special sense organs; respiratory, including speech organs; cardiovascular; reproductive, digestive, genito-urinary; hemic and lymphatic; skin; and endocrine. . . ." 45 C.F.R. § 84.3(j)(2)(i) (1987).

The phrase "asymptomatic" might suggest that such an asymptotically HIV-infected person would not comport with this definition. However, the Justice Department recently quoted the Surgeon General of the United States as stating:

In addition to acute flu-like illness, early stages of the disease may involve subclinical manifestations, i.e., impairments and no visible signs of illness. The overwhelming majority of infected persons exhibit detectable abnormalities of the immune system . . . [F]rom a purely scientific perspective, persons with HIV-infection are clearly impaired. They are not comparable to an immune carrier of a contagious disease such as Hepatitis B. Like a person in the early stages of cancer, they may appear outwardly healthy but are in fact seriously ill.

1988 Justice Department Memorandum, *supra* note 14, at 7-8 (quoting Letter from C. Everett Koop, M.D., Surgeon General, to Douglas W. Kmiec, Acting Assistant Attorney General, Office of Legal Counsel (July 29, 1988)).

Further, the physical impairment suggested by the Surgeon General is generally considered to limit major life activities associated, for instance, with procreation and intimacy. *Id.* at 9-13. Thus, asymp-

because of her infection?¹⁸ To what extent will courts force employers and others to make "reasonable accommodations" for people with AIDS?¹⁹ Thus, while federal and state laws exist, and generally cover people with AIDS, application of these laws to AIDS cases is far from formalistic.²⁰

This indeterminacy is illustrated by *AIDS and the Law's* several discussions of whether disability law would prevent employers from requir-

tomatic HIV-infected persons should be considered handicapped persons protected by § 504. Moreover, asymptomatic HIV-infected persons are also often "regarded as" being handicapped, and therefore should be protected by § 504 for that reason as well.

Not surprisingly, the federal courts that have considered this issue have found that asymptomatic HIV-infection is a "handicap" within the meaning of § 504. *See, e.g., Doe v. Centinella Hosp.*, Civ. 87-2514 (D.C. Cal. June 30, 1988) (order granting partial summary judgment holding HIV-infected individual to be "individual with handicaps" because he was perceived as such by defendant). *See also Ray v. School Dist. of DeSoto County*, 666 F. Supp. 1524 (M.D. Fla. 1987); *Thomas v. Atascadero Unified School Dist.*, 662 F. Supp. 376 (C.D. Cal. 1986); *Local 1812 v. Dep't of State*, 662 F. Supp. 50 (D.D.C. 1987). *Accord* *District 27 Community School Bd. v. Board of Educ.*, 502 N.Y.S.2d 325, 336 (Sup. Ct. 1986). However, the Supreme Court and the federal circuit courts have not yet definitively ruled on this issue.

18. In *Arline*, the Supreme Court wrote that "[a] person who poses a significant risk of communicating an infectious disease to others in the workplace will not be otherwise qualified for his or her job if reasonable accommodation will not eliminate that risk." *Arline*, 107 S. Ct. 1123, 1131 n.16.

Similarly, in passing the Civil Rights Restoration Act this year, Congress added an amendment to the Rehabilitation Act to clarify the term "otherwise qualified individual with handicaps" in the employment context. The amendment states that:

[F]or the purpose of [29 U.S.C.] sections 503 and 504, as such sections relate to employment, such term does not include an individual who has a currently contagious disease or infection and who, by reason of such disease or infection, would constitute a direct threat to the health or safety of other individuals or who, by reason of such disease or infection, is unable to perform the duties of the job.

Pub. L. No. 100-259, 56 U.S.L.W. 46 (Apr. 5, 1988); 134 CONG. REC. H587-8 (daily ed. Mar. 2, 1988).

The recent Justice Department Memorandum expounds on the "factual," and therefore generally uncertain, nature of this inquiry:

Based on current medical knowledge, *it would seem* that in *most* situations the probability that the AIDS virus will be transmitted is slight, and therefore as a matter of health and safety there will often be little, if any, justification for treating infected individuals differently from others . . . As the disease progresses . . . and conditions such as ARC or "full blown" AIDS affect the physical or mental capacity of the individual, *it may well* be that an "individualized inquiry" will reveal that such person is not otherwise qualified to participate.

In addition, current medical knowledge does *suggest the possibility* of specialized contexts where, even with respect to a person in the early stages of the disease, a court *might* find an individual to be not otherwise qualified. . . . The inquiry in each case will be a factual one. . . .

See 1988 Justice Department Memorandum, *supra* note 14 (emphasis supplied).

19. In *Arline*, the Supreme Court wrote that "[a]ccommodation is not reasonable if it either imposes 'undue financial and administrative burdens' on a grantee, or requires 'a fundamental alteration in the nature of [the] program.'" 107 S. Ct. at 1131 n.17 (citations omitted). One of the more troubling issues concerning HIV-infected workers is whether in a small, self-insured business the presence of an HIV-infected employee would pose such an "undue financial burden" on the employee health plan that the company could justify denying employment to that individual.

20. The indeterminacy of federal discrimination law is mirrored on the state level. Because § 504 applies only to recipients of federal funds, litigants must often turn to state discrimination laws for protection against discrimination in private employment, public accommodations, and housing. (Housing discrimination against handicapped persons is now also actionable under the federal Fair Housing Act. *See infra* text accompanying notes 60-61.) But before state laws can offer such protections, they each must be interpreted to decide whether AIDS, ARC, and/or asymptomatic HIV infection are covered disabilities; whether, for instance, nursing homes and doctors' offices are public accommodations; who is "otherwise qualified"; and what "reasonable accommodation" means, etc.

ing HIV tests as a condition of employment. Arthur Leonard, in his comprehensive chapter on AIDS in the workplace, writes:

Generally, handicap discrimination statutes are interpreted to forbid *discriminatory* use of tests, which means that employees who are members of a protected group may not be singled out for special testing not uniformly given to all employees or applicants. . . . However, there seems to be no general prohibition of *nondiscriminatory* medical testing in the private sector. Apart from those few jurisdictions which have specifically banned the use of antibody testing, and the restrictions noted under the Rehabilitation Act and comparable state and local regulations on the use of test results, it seems that employers are free to test without violating state and local handicap discrimination laws, although some local enforcement agencies have taken a different view of the matter.²¹

In a parallel discussion of the same subject in "Screening Workers for AIDS,"²² Mark Rothstein writes that:

The legality of various approaches to testing is no more settled than is their medical necessity. . . . Many state handicap-discrimination laws are worded quite generally and have not yet been interpreted judicially or administratively. Thus, it is not clear whether testing itself is generally illegal, though it is widely believed that the *use* of antibody test results in employment decision making is illegal absent a showing of job-relatedness.²³

Thus, Leonard concludes that "it seems that employers are free to test,"²⁴ while Rothstein concludes that "it is widely believed that the *use* of antibody test results . . . is illegal."²⁵

Even more interesting than the differing emphases of the authors' conclusions, is the carefully crafted language they use to frame these conclusions. Neither author is being evasive. The point is that the law governing this critical AIDS-related issue is simply not predictable.²⁶ While, as Dal-

21. Leonard, *Aids in the Workplace*, in AIDS AND THE LAW 109, 117 (H. Dalton, S. Burris & Yale AIDS Law Project eds. 1987).

22. Rothstein, *Screening Workers for AIDS*, in AIDS AND THE LAW 126, 135-37 (H. Dalton, S. Burris & Yale AIDS Law Project eds. 1987).

23. *Id.* at 135.

24. Leonard, *supra* note 21, at 117.

25. Rothstein, *supra* note 22, at 137.

26. To date, the most important case in this area involved testing of employees in the public workplace. *Glover v. Eastern Neb. Community Office of Retardation*, 686 F. Supp. 243 (D. Neb. 1988), *aff'd*, No. 88-1678 (8th Cir., Feb. 6, 1989). In *Glover*, the federal district court enjoined the implementation of a state program requiring mandatory HIV antibody and hepatitis (HBV) antibody testing of employees at a residential facility for mentally retarded persons. While the case included both a § 504 and a Fourth Amendment claim, the court's decision was based on the Fourth Amendment. 686 F. Supp. at 250. The court found that the state could not articulate a compelling reason for the testing program sufficient to justify this infringement on the employees' constitutional rights. *See also*, *Anonymous Fireman v. The City of Willoughby*, No. 88-1182 (U.S.N.D. Ohio filed May 11,

ton reminds us, "the principles and procedures that will guide decision-making are . . . already in place,"²⁷ the existence of such principles and procedures makes "AIDS law" no more (or less) certain than the "AIDS crisis" itself.

B. *The Unpredictability of The Application of Judicial Precedent*

Similar to the issues raised when applying an existing statute to a new field of law are those raised when applying judicial precedents to AIDS for the first time. For example, in *AIDS and the Law's* chapter entitled "Doctors and Patients,"²⁸ authors Belitsky and Solomon examine a physician's duty to warn her patient's sexual partners of the patient's HIV infection. The authors consider the doctor's ethical and legal responsibility to safeguard the patient's right to confidentiality. They then proceed to analyze the Court's decision in *Tarasoff v. Regents of the Univ. of Cal.*,²⁹ and its subsequent applicability to cases involving contagious diseases. After this discussion, the authors conclude, "[u]nder either a contagious disease or a *Tarasoff* analysis, it is likely courts will find that physicians and therapists have a duty to inform their patients' known sexual partners if the patient has AIDS."³⁰ While the authors' discussion is a helpful and concise summary of this area of the law, their conclusion is notably gauged in ambiguity ("it is likely").

This ambiguity reflects the sense of indeterminacy which governed a *Tarasoff*-like case that arose in Kansas in May of 1988. The ACLU was contacted by an individual who had been told by his health care providers, an HMO, that it was about to notify his estranged wife of his HIV test results. The man had been separated from his wife for nearly two years (since October of 1986) and had not had sex with her during that time. He tested positive for the HIV antibody in March of 1987. The HMO subsequently tested his wife on two occasions, in the spring and fall of 1987, and knew she was uninfected. Nonetheless, in May of 1988, fourteen months after it initially discovered the man's positive test result, the HMO announced that it was going to notify the wife.

1988) (order granting plaintiff's motion for a temporary restraining order to enjoin implementation of municipality's HIV testing program of firemen).

27. Dalton, *supra* note 1, at xii.

28. Belitsky & Solomon, *Doctors and Patients: Responsibilities in a Confidential Relationship*, in *AIDS AND THE LAW* at 201-09 (H. Dalton, S. Burris & Yale AIDS Law Project eds. 1987).

29. 17 Cal. 3d 425, 551 P.2d 334, 131 Cal. Rptr. 14 (1976) (*Tarasoff II*). As explained by Belitsky and Solomon:

The California Supreme Court [in *Tarasoff*] imposed a duty on psychotherapists to protect third persons from the potentially dangerous acts of their patients. . . . *Tarasoff* is particularly significant in the AIDS context, because the transmission of AIDS can, in some instances, be viewed as the result of intentional action. Moreover, *Tarasoff* reaffirmed a physician's duty to protect third parties from dangers created by a patient's illness.

Belitsky & Solomon, *supra* note 28, at 203-04.

30. Belitsky & Solomon, *supra* note 28, at 207.

At times during this case, the HMO's lawyers expressed their concern as a fear of *Tarasoff* liability, rather than as a consideration for the wife's safety, if they did not warn the wife, they feared the clinic might itself face liability some day. There was, however, little reason to warn the wife. There was no threat of imminent harm to her since the couple was separated and thus the infected husband was not likely to have sexual relations with her. Additionally, since the HMO had tested the wife and knew her to be uninfected, it knew that she was not an unknowing carrier of the virus. Finally, although the HMO claimed the husband's HIV infection should have affected his visitation rights, nothing in the medical literature suggested that visitation posed any threat to the children.³¹ There was not, therefore, any logical reason to notify the wife of the estranged husband's HIV-test results. We expected a court would side with the husband, notwithstanding the principles announced in *Tarasoff* and its progeny.

In May of 1988, a Kansas court issued a temporary restraining order prohibiting the HMO from divulging the confidential information to the estranged wife, and in October the court permanently enjoined the HMO from disclosing the plaintiff's test results.³²

While the Kansas case is a meaningful precedent supporting the confidentiality of HIV-related information, its value outside of the peculiar and narrow facts of the case is difficult to assess.³³ If the HMO had not known that the wife was uninfected and suspected that she might be an unknowing carrier of the virus, or, if the husband and wife still engaged in sexual relations with one another and there had been some threat of imminent infection to the wife, the case might have been decided very differently.

Despite the existence of guiding principles and precedent borrowed from other areas of the law, the outcomes of these types of cases are not, as with the HIV testing situation, predictable in any certain or determinant fashion. Again, the "existence" of such principles and procedures

31. See, e.g., Friedland & Klein, *Transmission of the Human Immunodeficiency Virus*, 317 NEW ENG. J. MED. 1125, 1132 (Oct. 29, 1987) (showing that of 30,000 cases of AIDS in United States as of February 1987, there were no documented cases of casual transmission of HIV through household contact such as sharing "beds, toilets, bathing facilities, and kitchens, as well as items likely to be soiled by patients' saliva or bodily fluids (e.g., eating utensils, plates, drinking glasses, and towels)."). See also *Stewart v. Stewart*, 521 N.E.2d 956 (Ind. Ct. App. 1988) (husband's visitation rights should not be affected because he was infected with HIV); "Jane" W. v. "John" W., 137 Misc. 2d 24, 519 N.Y.S.2d 603 (1987) (husband's visitation rights should not be affected because he was infected with HIV); *Wallace v. Wallace*, No. VFL 013212, Calif. Sup. Ct., San Bernardino City June, 1988; *Courts Says Father With AIDS Should Have Custody Of Son*, in AIDS POLICY & LAW 2 (November 2, 1988).

32. *Doe v. Prime Health/Kansas City, Inc.* No. 88-C-5149, slip op. at 11 (Dist. Ct. Johnson County, Kan., Oct. 17, 1988).

33. Indeed, in his decision in *Prime Health*, Judge Chipman wrote that "[t]he court is aware that this matter presents a very serious and sensitive issue, and reminds the parties that this decision is to be applied only to the parties in this particular case and rendered only upon the facts presented." *Id.* at 5.

does not necessarily relieve the pervasive sense of uncertainty which characterizes *AIDS and the Law*, and the AIDS crisis itself.

C. *The Existence of Conflicting Applicable Laws or Precedent*

Differing interpretations of existing law or precedent, such as those presented in the section 504 cases and in the Kansas case, are not the only causes of indeterminacy in AIDS law. The possible applicability of different laws and/or precedents creates a third area of uncertainty in the legal system.

A case litigated by the ACLU in South Carolina is illustrative. In March of 1988, South Carolina's Department of Health and Environmental Control "quarantined" an HIV-infected woman at the state mental hospital. The Department declared that, in addition to being infected with HIV, the quarantined woman was mentally incompetent, an intravenous drug user, and a prostitute, and thus a threat to the public health. Although depriving "Robin"³⁴ of her liberty, the state had not given her notice or an opportunity to be heard before it isolated her.

Three South Carolina commitment statutes could have been applied to Robin's situation. Two were fairly modern laws, dealing with the involuntary commitment of mentally incompetent persons³⁵ and chemically dependent persons.³⁶ Both of these laws contained significant procedural protections. The third statute, dating from the turn of the century, allowed for the indefinite quarantine of an individual without any procedural protections simply upon a finding by the Department that the person presented a threat to public health.³⁷

Not surprisingly, Robin had been committed pursuant to the third statute. A habeas corpus petition was prepared seeking to have Robin's commitment declared unconstitutional and thereby to force her release.³⁸ In the meantime, though not as a consequence of this case, the South Carolina legislature passed a new quarantine statute after the commencement of the ACLU's efforts on Robin's behalf, which created yet another avenue under which the state could act against Robin.³⁹

34. Only the client's first name was used in an effort to safeguard her privacy.

35. S.C. CODE ANN. §§ 44-17-510 to 520 (Law. Co-op. 1985).

36. *Id.* at §§ 44-51-50 to 70.

37. *Id.* at §§ 44-1-80, 44-29-90.

38. The ACLU also expected to bring a case under 42 U.S.C. § 1983 seeking a declaration that the obsolete quarantine statute was unconstitutional and enjoining its further implementation. We envisioned that such a ruling from the federal court system would have wide precedential value, especially in states which still have archaic quarantine statutes.

39. The new statute, though still unconstitutional from the ACLU's perspective, did contain some indicia of due process. S.C. CODE ANN. § 44-29-115 (Law Co-op, 1988) now requires the Department, prior to isolating an individual, to file a petition with the probate court specifying the "harm thought probable and the factual basis for this belief." The person at issue is entitled to representation and to an appeal. The standard of proof is set forth as follows: "If the court, after due notice and hearing, is satisfied that the petition is well founded, it may order that the person be isolated." *Id.* The court ordered isolation cannot last more than 90 days.

Ultimately, Robin's case was decided without the ruling as to the constitutionality of the quarantine statute. Despite the existence of the quarantine order, the Department eventually sought to have Robin involuntarily committed pursuant to the chemical dependence statute, as well, and she was granted the state court hearing called for by that statute. At that hearing, the ACLU was able to show that there was no evidence in the record supporting commitment on these grounds, and Robin was released, although she was involuntarily ordered to undergo outpatient drug treatment. The state dissolved the quarantine order. In sum, this case exemplifies the indeterminacy that can be created, although the "principles and procedures for decision-making are, for the most part, already in place,"⁴⁰ by the possible application of a variety of such principles and procedures.

In *AIDS and the Law*, Frederic C. Kass's chapter, "Schoolchildren with AIDS,"⁴¹ provides an insightful exploration of this theme. Kass reviews three cases involving a single issue—whether schoolchildren with AIDS should be admitted to the classroom—each of which turned on a different legal issue. In one case from Queens, New York,⁴² section 504 was viewed as the governing statute: "The court ruled that automatic exclusion of schoolchildren with AIDS would have violated [section 504]."⁴³ In a second case from Indiana,⁴⁴ the Education for All Handicapped Children Act (EHA),⁴⁵ was viewed as the governing statute.⁴⁶ In a third case from New Jersey,⁴⁷ the admission of two HIV-infected children turned largely on whether state administrative regulations had been properly enacted.⁴⁸

In some circumstances, choices among the statutes and regulations can lead to contradictory results. For example, the procedural requirements of the EHA and section 504 differ greatly: the EHA requires exhaustion of administrative remedies (which can be quite long and time consuming) before a case can be brought in federal court, while the Rehabilitation Act has been interpreted as not requiring exhaustion.⁴⁹ Because of these exhaustion requirements, school boards tend to promote the applicability of

40. Dalton, *supra* note 1, at xiii.

41. Kass, *Schoolchildren with AIDS*, in AIDS AND THE LAW 66 (H. Dalton, S. Burris & Yale AIDS Law Project eds. 1987).

42. *Id.* at 73 (citing *In re District 27 Community School Bd. v. Board of Educ.*, 502 N.Y.S.2d 325 (Sup. Ct. 1986)).

43. Kass, *supra* note 41, at 75.

44. *Id.* at 76 (citing *White v. Western School Corp.*, No. IP-85-1192-C (S.D. Ind. Aug. 16, 1985)).

45. 20 U.S.C. § 1400 (1982 & Supp. III 1986).

46. Kass, *supra* note 41, at 76-77.

47. *Id.* at 77-78 (citing *Board of Educ. v. Cooperman*, 209 N.J. Super. 174, 507 A.2d 253 (App. Div. 1986)).

48. *Id.*

49. See, e.g., *Shuttleworth v. Broward County*, 639 F. Supp. 654, 657-58 (S.D. Fla. 1986) (exhaustion of administrative remedies is not prerequisite to filing claim for relief under § 504 of Rehabilitation Act).

the EHA and use it as a defense in section 504 cases, asking federal courts to dismiss section 504 cases for failure to exhaust EHA administrative procedures.⁵⁰

A second example of overlapping and possibly contradictory extant legal standards occurs with regard to the issue of antibody testing by the government. Such testing may be challenged as a constitutional violation arising under the Fourth Amendment and as a legal question arising under the Rehabilitation Act.⁵¹ In *Glover*,⁵² the district court halted a testing program on constitutional grounds, without comment on the plaintiffs' section 504 claims. On appeal,⁵³ the state argued that the court must have decided the Rehabilitation Act issue against the plaintiffs, otherwise it would never have reached the constitutional question. Thus, at present, one could read the applicable statute and the applicable constitutional standard as creating conflicting results.

In sum, existing statutes and precedent are, as *AIDS and the Law* quite proficiently shows, the obvious materials upon which to draw in AIDS-related legal situations. And, as editor Dalton insists, these extant legal materials provide a structure and framework for the manner in which AIDS-related law will develop. However, *AIDS and the Law* also illustrates the indeterminacy that is inherent in the applications of these existing materials—the uncertainty of initial applications of existing, and sometimes conflicting, laws and precedents to AIDS-related situations. While there is truth in Dalton's statement that "the practical differences [between AIDS and old problems] . . . can be apprehended and taken account of by the law with relative ease,"⁵⁴ there is truth in the converse, as well. The law does not provide an organized oasis outside the social reality of the AIDS crisis, but rather helps form, and is itself formed by, the governing uncertainty of that social reality.

II. THE DESTABILIZING CONSEQUENCES OF NEW LAWS

As if there was not enough indeterminacy in attempting to apply existing legal doctrines to AIDS, state legislatures and Congress are constantly changing the available legal materials.

In 1987, more than 450 bills concerning AIDS were introduced in state

50. See, e.g., *Doe v. Belleville Pub. School Dist. No. 118*, 672 F. Supp. 342 (S.D. Ill. 1987) (EAH did not apply to student with AIDS and thus he was not required to exhaust EAH administrative remedies and could bring § 504 claim in federal court).

51. See *Local 1812 v. Department of State*, 662 F. Supp. 50 (D.D.C. 1987). The two discussions of employment-related antibody testing in *AIDS and the Law* (see *supra* text accompanying notes 21–26) are examinations of testing in the private sector. They focus on the Rehabilitation Act because such private employer testing does not raise constitutional issues.

52. 686 F. Supp. 243 (D. Neb. 1988); See *supra* note 26.

53. 686 F. Supp. 243 (D. Neb. 1988) *aff'd*, No. 88-1678 (8th Cir. Feb. 6, 1989).

54. Dalton, *supra* note 1, at xiii.

legislatures across the country.⁵⁵ Despite the often haphazard quality of many of these state legislative responses,⁵⁶ they have largely shaped the rules governing relationships between persons with AIDS and society. How these rules will be enforced and how they will affect the social relationships they are intended to govern is undetermined.⁵⁷ Yet, the contribution of state legislatures to the development of AIDS-related law is difficult to overstate.

One of the overwhelming difficulties of compiling a book about a new and changing area of law, and AIDS-related law in particular, is how to take account of these legislative developments. The focus of *AIDS and the Law* is litigative, not legislative. The book does not include a chapter or section which attempts to summarize these legislative initiatives. This omission implies that the legal materials to be drawn on already exist.⁵⁸ However, the book also contains a competing vision of a state of affairs that may soon change with the passage of new legislation.

For instance, new regulations significantly altered one section of *AIDS*

55. Lewis, *Acquired Immunodeficiency Syndrome: State Legislative Activity*, 258 J. AM. MED. A. 2410 (Nov. 6, 1987). Lewis groups these proposed laws into ten subject areas: (1) antibody testing, (2) blood and blood products, (3) confidentiality, (4) employment, (5) housing, (6) informed consent, (7) insurance, (8) marriage, (9) prison population, and (10) reporting. *Id.*

56. In some states, legislators have attempted to deal with a number of AIDS-related issues in one, seemingly comprehensive, bill. See, e.g., H.R. Res. 2067, 64th Or. Leg. Assembly Reg. Sess. (1987) (amending sections of Oregon public health laws dealing with name reporting, contact tracing, isolation, quarantine, and other preventive public health measures; requiring informed consent for HIV testing; mandating confidentiality of HIV test results; providing immunity from civil liability to health care providers who comply with confidentiality provisions; directing establishment of prevalence studies and education curricula; ordering development of plan for dealing with AIDS in prisons; and requiring HIV testing for persons convicted of sex and drug-related crimes).

Other states have enacted a hodgepodge of disparate statutes. In Illinois, for example, at least 11 AIDS-related bills were passed at the conclusion of the 1987 Congressional term and sent to the governor for his signature. H.R. Res. 100, 1987 Ill. Leg., Regular Sess. (requiring informed consent for HIV tests and confidentiality of results); S. Res. 100, 1987 Ill. Leg., Regular Sess. (requiring informed consent for HIV tests and confidentiality of results); S. Res. 100, 1987 Ill. Leg., Regular Sess. (incentive payments for care of AIDS patients in nursing homes); S. Res. 994, 1987 Ill. Leg. Regular Sess. (demonstration projects for long-term care; establishment of state AIDS Foundation); H. Res. 736, 1987 Ill. Leg. Regular Sess. (AIDS Registry, public employee education, expansion of Medicaid-eligible services); ILL. S. Res. 550, 1987 Ill. Leg. Regular Sess. (AIDS education to accompany sex education); S. Res. 1225, 1987 Regular Sess. (abstinence from sex until marriage education to accompany sex education); S. Res. 85, Regular Sess. (1987) (testing of marriage license applicants, inmates, and hospital admittees); H. Res. 2044, 1987 Ill. Leg. Regular Sess. (testing of marriage license applicants, convicted sex and drug offenders, and requiring notification of principals when pupils have HIV antibodies); Ill. S. Res. 651, 1987 Ill. Leg. Regular Sess. (authorizing Department of Public Health to require reporting of HIV-infected individuals and to trace sexual contacts of such persons, and codifying quarantine procedures); H. Res. 2682, 1987 Ill. Leg. Regular Sess. (mandating contact tracing for HIV-infected persons and requiring name reporting of seropositive persons to health department). The governor then fashioned his own comprehensive AIDS bill by choosing among those put before him as he saw fit. "Broad AIDS Law Signed In Illinois," N.Y. Times, Sept. 21, 1987, at B7.

Some states have simply enacted one or two single issue AIDS-related measures. Louisiana, for example, passed two laws in 1987 concerning AIDS, one criminalizing intentional exposure to the AIDS virus, H. Res. 1728, 1987 La. Leg. Regular Sess. and a second requiring clinical testing for AIDS prior to issuance of a marriage license, 1987 H.R. 336, La. Leg. Regular Sess. (1987).

57. See *supra* Part I.

58. Dalton, *supra* note 1, at xii.

and the Law between the time the book was completed and the time it was published. A "NOTE" at the beginning of *AIDS and the Law's* excellent section on intravenous drug abusers reads simply: "As this book went to press, the federal confidentiality regulations discussed at pp. 266-76 were being renumbered and significantly revised, effective Aug. 10, 1987. The new regulations, which place fewer restrictions on the release of information, appear at 52 Fed. Reg. 21,796 (1987)."⁵⁹ The NOTE describing the changes in the confidentiality regulations is admirable and brings the reader as up to date as possible.

Similarly, the recent passage of congressional amendments to the Fair Housing Act,⁶⁰ has substantially affected the subject matter of Daniel Mandelker's chapter on AIDS and Housing. These amendments extend the Fair Housing Act's protections to handicapped persons and specifically to people with AIDS, ARC, and HIV infection.⁶¹

While these subsequent legislative developments affect the value of the legal discussions in these chapters, other chapters, specifically, John F. Decker's chapter on Prostitution as a Public Health Issue⁶² and Jane Aiken's chapter on Education as Prevention,⁶³ appear to be geared toward ongoing legislative debates. Decker summarizes state legislative proposals concerning AIDS and prostitution and considers the medically unwarranted reactions of most of these measures. His chapter was one of the first published arguments⁶⁴ rationally examining the relationship between prostitution and the spread of AIDS.⁶⁵

59. O'Neill, *Intravenous Drug Abusers*, in *AIDS AND THE LAW* 253 (H. Dalton & S. Burris, Yale AIDS Law Project eds. 1987).

60. Fair Housing Act Amendments of 1988, H.R. 1158, as amended, 100th Cong., 2d Sess., 134 CONG. REC. 46491 (Aug. 8, 1988).

61. *Id.* Mandelker did not appear to recognize the effect the Fair Housing Act amendments would have on AIDS-related housing issues. His acknowledgement of the pending legislation that would extend the Act's protections to handicapped persons appears only in an endnote, which the reader must (and probably will not) turn to the back of the book to read. Mandelker, *Housing Issues*, in *AIDS AND THE LAW* 326 n.18 (H. Dalton & S. Burris, Yale AIDS Law Project eds. 1987).

62. Decker, *Prostitution as a Public Health Issue*, in *AIDS AND THE LAW* 81 (H. Dalton & S. Burris, Yale AIDS Law Project eds. 1987).

63. Aiken, *Education as Prevention*, in *AIDS AND THE LAW* 90 (H. Dalton & S. Burris, Yale AIDS Law Project eds. 1987).

64. Recent studies have added support to Decker's conclusion. See, e.g., *Prostitution: Widespread Use of Condoms Said to Provide Small Risk*, in *AIDS POLICY & LAW* (Oct. 5, 1988); Rosenberg & Weiner, *Prostitutes and AIDS: A Health Department Priority?*, 78 AM. J. PUB. HEALTH 418 (1988); Quinn, et al., *Human Immunodeficiency Virus Infection Among Patients Attending Clinics for Sexually Transmitted Diseases*, 318 NEW ENG. J. MED. 197, 199 (1988); U.S. Centers for Disease Control, *Antibody to Human Immunodeficiency Virus in Female Prostitutes*, 257 J. AM. MED. A. 2011 (Apr. 17, 1987); *AIDS Among Prostitutes Not as Prevalent as Believed, Studies Show*, N.Y. Times, Sept. 20, 1988, at B1, col. 2 (city ed.).

65. In contrast to this rational examination of this issue, many legislators and commentators automatically assume the existence of some relationship between AIDS and prostitution. For example, the President's AIDS Commission, in its final report, stated in a section entitled "Criminalization of HIV Transmission," that an "Obstacle to Progress" in this area is that "[p]enalties for prostitution are too lenient and enforcement of prostitution laws is erratic." THE PRESIDENTIAL COMMISSION ON THE HUMAN IMMUNODEFICIENCY VIRUS EPIDEMIC REPORT 130 (June 1988). Accordingly, the Commission recommended that "Prostitution laws should be strictly enforced." *Id.* at 131.

Similarly, in her chapter on Education as Prevention,⁶⁶ Jane Aiken appears to have foreseen Congress' enactment of the "Helms Amendment"⁶⁷ and has lucidly addressed its impact and legality. The Helms Amendment provides that no funds from the Centers for Disease Control "shall be used to provide AIDS education, information, or prevention materials and activities that promote or encourage, directly, homosexual activities."⁶⁸ Aiken's chapter is one of the first considerations of the legal issues, such as the First Amendment ramifications, raised by the Helms Amendment, although it was written before the Amendment was proposed.⁶⁹ Larry Gostin's chapter on Traditional Public Health Strategies⁷⁰ also attempts to deal with ongoing legislative issues and the legality of many of these solutions.

Just as the publication of *AIDS and the Law* was affected, and in some cases superceded, by breaking legislative developments, so to litigative efforts to define AIDS law are also prone to these external influences. For example, in the South Carolina case described above, the ACLU busily prepared a case challenging the constitutionality of a statute which was about to be displaced by a new statute. Similarly, coincidental to the events in the Kansas case discussed above, Kansas passed a new law concerning the confidentiality of HIV test results.⁷¹ This subsequent, external development impacted the outcome of the case,⁷² though it was beyond the control of those involved in the case and was not a consequence of the case.

These external, often legislative, developments largely constitute what is becoming AIDS law, and clearly demonstrate that this body of the law is constantly changing. *AIDS and the Law*, in its attempt to bring order to

This "obstacle" and the "recommendation" are accompanied by absolutely no textual material discussing prostitution, much less any discussion attempting to show a connection between prostitution and AIDS. Therefore, there appears to be no basis for the Commission's recommendation that prostitution laws should be more strictly enforced. Nor is there any support for the assumption inherent in such a recommendation—namely, that enforcement of prostitution laws would impede the spread of HIV.

66. Aiken, *supra* note 63.

67. Labor-Health and Human Services Appropriation Bill for Fiscal Year 1988, Pub. L. No. 100-102, § 514.

68. *Id.* at § 514(a). The Helms Amendment also requires all AIDS education activities and materials to "emphasize abstinence from sexual activity outside a sexually monogamous marriage (including abstinence from homosexual sexual activities)." *Id.* at § 514(b).

If a recipient of CDC funds contravenes this law in any respect, the Act penalizes the infraction by providing that "no further funds shall be provided to a recipient." *Id.*

69. Aiken's analysis anticipated the analysis the ACLU undertook prior to filing a case challenging the legality of the Helms Amendment. *Gay Men's Health Crisis v. Bowen*, No. 88-7482 (S.D.N.Y., complaint filed Oct. 20, 1988).

70. Gostin, *Traditional Public Health Strategies*, in *AIDS AND THE LAW* 47 (H. Dalton, S. Burris & Yale AIDS Law Project eds. 1987).

71. See S. Res. 686, 1988 Kans. Sess. 1359; H. Res. 2759, 1988 Kans. Sess. 1368.

72. Although these bills did not control the outcome of the case, Judge Chipman concluded that they "reinforce and demonstrate that it is the public policy of the state to impose a duty of confidentiality not only on doctors who possess information concerning the identity of HIV patients, but on others who acquire that information as well." *Prime Health*, No. 88-C-5149, slip opinion, 11, 12.

AIDS law, in some places submerges these destabilizing influences; in other places, the book's attempt to control the AIDS crisis involves recognition and anticipation of these future developments. This inclusion of the tension between order and uncertainty in AIDS-related law is one of the strengths of the book. It is a strength because it reflects the general desire of the legal system to order uncertainty, and it is a strength because it parallels another, non-legal, effort to order the specific uncertainty of the AIDS crisis—the efforts of people with AIDS to come to grips with AIDS itself.

III. THE PWA EMPOWERMENT MOVEMENT

AIDS and the Law does not fully capture the efforts of people with AIDS (PWAs) to deal with the anxiety of the AIDS crisis. This absence is understandable. The voices of people with AIDS were not loudly heard nor was their plight widely understood at the time *AIDS and the Law* was published, and a book such as *AIDS and the Law* is, like its legal conclusions, bound to a specific historical moment. "Such are the trials," editor Dalton writes, "of trying to produce a book about an epidemic when its collateral consequences continue to multiply."⁷³

In his preface to *AIDS and the Law*, Dalton describes a meeting shortly before the book's publication at which a newly recruited student asked: "Do you have a chapter on the licensing of new drugs?"⁷⁴ With "mild embarrassment," Dalton answered the student: "[I]n soliciting the manuscripts fifteen months earlier, we had not anticipated how important the issue would become."⁷⁵ In fact, this subject, which was coming to the fore just as *AIDS and the Law* was being published, is tied to the development of the PWA empowerment movement. The movement represents the formal expression of people with AIDS' attempts at ordering their ordeal, and this movement interestingly parallels, and sometimes intersects with, *AIDS and the Law's* attempts to order the legal aspects of the AIDS crisis.

The People with AIDS empowerment movement dates to the Second National AIDS Forum held at the National Lesbian and Gay Health Conference in Denver in June of 1983. PWAs at the conference ratified the "Founding Statement of People with AIDS/ARC" (the "Denver Principles"),⁷⁶ which included recommendations for health care professionals, people with AIDS, and the public. The recommendations are perhaps best summarized by the statement which accompanies them: "We

73. Dalton, *supra* note 1, at xv.

74. *Id.*

75. *Id.*

76. *Founding Statement of People with AIDS/ARC: "The Denver Principles,"* in SURVIVING AND THRIVING WITH AIDS: HINTS FOR THE NEWLY DIAGNOSED 128-29 (M. Callen ed. 1987) [hereinafter *The Denver Principles*].

condemn attempts to label us as 'victims', which implies defeat, and we are only occasionally 'patients' which implies passivity, helplessness and dependence upon the care of others. We are 'people with AIDS.'"⁷⁷

The purpose of the PWA empowerment movement and of the Denver Principles is also summarized by the Mission Statement of the National Association of People with AIDS (NAPWA):

We are people with AIDS and people with AIDS-Related Complex (ARC) who can speak for ourselves to advocate for our own causes and concerns. We are your sons and daughters, your brothers and sisters, your family, friends and lovers. As people now living with AIDS and ARC, we have a unique and essential contribution to make to the dialogue surrounding AIDS and we will actively participate with full and equal credibility to help shape the perception and reality surrounding this disease.

We do not see ourselves as victims. We will not be victimized. We have the right to be treated with respect, dignity, compassion and understanding. We have the right to lead fulfilling, productive lives—to live and die with dignity and compassion.⁷⁸

The PWA empowerment movement has effected the following types of changes, each with its own legal consequences. First, on an individual level, many PWAs have upset the traditional roles assigned by our society to "doctors" and "patients" and, in so doing, have challenged the existing legal relationships between doctors and patients. The Denver Principles, for instance, call on health care professionals to "[g]et in touch with their feelings (*e.g.*, fears, anxieties, hopes, etc.) about AIDS, and not simply deal with AIDS intellectually."⁷⁹ Furthermore, the Principles recognize the rights of PWAs to "full explanations of all medical procedures and risks, to choose or refuse their treatment modalities, to refuse to participate in research without jeopardizing their treatment and to make informed decisions about their lives."⁸⁰ These principles have been effectuated in a number of ways. For instance, PWAs regularly publish newsletters which share information about doctors and about treatments.⁸¹ Similarly, PWAs have formed "Buyers Clubs" which have arranged for

77. *Id.*

78. *Statement of Purpose of The National Association of People with AIDS*, in *SURVIVING AND THRIVING WITH AIDS: HINTS FOR THE NEWLY DIAGNOSED* 130 (M. Callen, ed. 1987).

79. *The Denver Principles*, *supra* note 76, at 128.

80. *Id.*

81. The People With AIDS Coalition in New York publishes a magazine, the *NEWSLINE*, which is a collection of PWA-written articles and letters directed to other PWAs concerning a wide range of issues including different types of experimental drugs, the side effects they have been experiencing, how to get drugs and where to get them cheapest, which doctors can be trusted, etc. According to the October, 1988 *NEWSLINE*, PWA newsletters also exist in San Francisco, Dallas, Minneapolis, Philadelphia, and Washington, D.C.. PWA NEWSLETTERS, 37 *NEWSLINE* 28 (Oct. 1988).

the purchase and distribution of experimental treatments to PWAs and PWARCs.

The legal consequences of this type of empowerment are typified by the following example. In the spring of 1988, the ACLU was contacted by an individual (Steve)⁸² who had been a participant in an experimental drug trial which had ended in February. Steve believed he had been induced into entering the trial two years ago with, *inter alia*, the promise that he could continue receiving the treatment indefinitely and without cost at the conclusion of the trial if he so desired. He had been faithful to the experimental drug for two years, even ignoring his doctors' advice to go on AZT during a period of particular illness, and he now wanted to continue receiving it although the trial's results had been disappointingly inconclusive.

The company, however, said that it could no longer provide Steve with the treatment, because, among other things, the Food and Drug Administration (FDA) would not allow it to make assertions about the drug's efficacy. The company feared that providing the drug to Steve would be tantamount to claiming that it worked. Moreover, the doctors, who were involved with the drug trial and who continued to be Steve's treating physicians, did not share his recollection of the promises that were made at the beginning of the trial. They also did not believe the drug was effective and were not enthusiastic about Steve continuing treatment.

Despite his doctors' doubts about the drug and their doubts about his memory of the promises that were made, Steve wanted to continue on the treatment *and* was convinced that he had been promised that he could. He found the strength to empower himself, to challenge his doctors, whom he generally trusted and relied on to provide him care, and to challenge a large drug company. He won. The case was settled with a series of phone calls to the company's headquarters, and Steve has been supplied with the experimental treatment free of charge ever since. Although Steve's case never resulted in formal litigation, it nonetheless raised legal issues involving contract law and FDA law which were not anticipated when *AIDS and the Law* was published.

A second aspect of this movement is the collectivization of PWAs and persons concerned about AIDS, particularly gay men and lesbians. This collectivization has created unique care communities which have radically reconceptualized the ways in which we think about "family" and "caring." For instance, every large city in the country now has an AIDS service organization. These organizations typically provide a wide range of services for PWAs in their area, many of which are not provided by the government or by traditional health care providers. Such services include

82. "Steve" is not the client's real name but is used to protect his privacy.

the provision of "buddies" to people with AIDS, and the provision, in a sense, of families to people who have often been abandoned by their own.

AIDS service organizations also provide financial services to people with AIDS free of charge. Such services generally include information about, and help receiving, benefits such as (in New York City) social security disability, supplemental security income, unemployment compensation, Medicaid, New York City income maintenance welfare, New York State disability, insurance, and housing. In addition, legal centers at AIDS organizations offer services such as the preparation of wills and powers of attorney and referrals for larger legal problems like discrimination cases.

AIDS and the Law does not address these issues; it is very consciously not a legal handbook for people with AIDS. For example, although one chapter is authored by Mark Senak,⁸³ who was the legal director of the Gay Men's Health Crisis in New York for a number of years, it does not deal with the kinds of legal work done for PWAs by GMHC, but is a general history of the gay rights movement. Similarly, Mark Scherzer's Insurance⁸⁴ chapter is an overview of the insurance industry, not a primer on how to help people with AIDS find insurance and gain access to benefits.⁸⁵ Obviously, a choice was made to focus on these larger issues rather than to provide direct advice for PWAs and their lawyers. This choice was doubtlessly affected by, among other factors, the time period in which the choice was made, namely, before PWA empowerment brought issues directly involving PWAs to the center of concern.

Beyond individual empowerment and collectivization, a third aspect of PWA empowerment has been that PWA groups and AIDS service organizations have become forceful lobbies on issues of importance to them. The legal consequence of such lobbying is, quite simply, that the AIDS-related laws emanating from state legislatures and Congress have come to reflect the concerns of PWAs and AIDS advocates.

In addition to traditional lobbying and advocacy, PWAs have taken their anger about government inaction and societal indifference to the streets—picketing, demonstrating, and engaging in civil disobedience around issues of importance to them. In March of 1987, an AIDS activist group was formed in New York City and began meeting weekly at the Lesbian and Gay Community Service Center calling itself ACT-UP, or the AIDS Coalition to Unleash Power. A year and a half later, the weekly ACT-UP meetings are attended by several hundred people. Simi-

83. Senak, *The Lesbian & Gay Community in AIDS AND THE LAW* 290 (H. Dalton, S. Burris & Yale AIDS Law Project eds., 1987).

84. Scherzer, *Insurance*, in *AIDS AND THE LAW* 185 (H. Dalton, S. Burris & Yale AIDS Law Project eds., 1987).

85. Scherzer has written excellent pieces about these more specific issues in other places. Scherzer, *Insurance*, in *LAMBDA LEGAL DEFENSE AND EDUCATION FUND INC.: AIDS LEGAL GUIDE* 5-1 to 5-8 (A. Rubinfeld 2d ed. 1987); Scherzer, *Insurance and AIDS*, in *NATIONAL LAWYERS GUILD: SEXUAL ORIENTATION AND THE LAW* 16-1 to 16-30 (R. Achtenberg ed. 1987).

lar groups have sprung up around the country, loosely collected under a national umbrella organization, ACT-NOW (AIDS Coalition to Network, Organize and Win).

ACT-UP has taken lawyers who work with AIDS and with people with AIDS into areas of law not contemplated when *AIDS and the Law* was published. For instance, in March of 1988, to celebrate their first anniversary, 110 members of ACT-UP were arrested for sitting, nonviolently, in the middle of the street during the morning Wall Street rush hour. They were protesting the government's lack of interest in developing AIDS therapies and did so on Wall Street to denounce what they viewed as Wall Street's acquiescence to this indifference. Their posters read, "The Federal Interest Rate on AIDS—0%."

The 110 ACT-UP members were charged with disorderly conduct and resisting arrest. They pleaded not guilty and moved to dismiss the charges "in the interest of justice," basing the motion on an argument that their actions were a justified response to this country's AIDS policy. What follows is the Affidavit of ACT-UP member Michael Cowing, which supported the protesters' motion to dismiss.⁸⁶ The affidavit is a product of the legal system's effort to control the AIDS crisis. It also represents the expression of a person in the AIDS community struggling to take control of the AIDS crisis. It is, as such, an intersection of the movements described in this essay. I have reprinted the affidavit in full because I believe such a document is crucial to understanding AIDS law, yet such a voice cannot be found in *AIDS and the Law*.

IV. AFFIDAVIT OF MICHAEL COWING: "WHY I PARTICIPATED IN THE CIVIL DISOBEDIENCE ACTION ON MARCH 25, 1988"

Richard died in July, 1984. He had just turned 30. He was an historian and had one of the finest minds I have ever known. He was diagnosed with AIDS-related pneumonia and fourteen days later he was gone. His last two weeks were agonizing for him. That was 1984. So little was known about the disease—so few drugs were available. Had more treatments been available, he might have been saved. He can never be replaced.

Victor became ill in the Spring of 1986. He had a persistent cough and sporadic fevers. Eventually he became too sick to work and had to stay home confined to bed. His money ran out and he lost his apartment so he had to go home to Ohio to stay with his family—they didn't even want him. They were ignorant about AIDS and they were afraid. It was 1986 and very little information was available about the disease. Although responsible physicians and

86. Affidavit of Michael Cowing filed with the Criminal Court in the Borough of Manhattan, New York County (on file with ACLU) [hereinafter Affidavit].

scientists had gone on record as stating that the AIDS virus was not casually transmitted, the information was not made available to the general public on a widespread basis. Victor developed Toxoplasmosis, an infection in the brain, which later progresses into AIDS dementia. His mind completely disintegrated and he died in September of that same year, but by then he was no longer the friend I had known. The Victor I had come to know and love was a gentle, brilliant man. He was a linguist and had a curiosity about life and people that was immediately disarming. He was 36 years old. His death was a terrible waste. He might have held on till better therapies became available but then it was 1986 and so little was known—so few effective treatments were available.

Kenneth was a funny kind of guy. He had been confused the last couple of years, seemed to have no direction, didn't know what he wanted out of life. Then in the summer of 1986, he decided to go to law school. Suddenly, he was filled with purpose and drive. He applied for and was accepted by Cardoza Law School and enrolled that fall. He immediately took to the curriculum and established a 4.0 grade point average that he maintained until he left school. In January of 1987, he came down with a terrible flu that he just couldn't shake. He got weaker and weaker and lost a frightening amount of weight. He was diagnosed with AIDS in mid-February. By the first week of March, he was gone. He had AIDS-related pneumonia and didn't respond to the treatments that were available. It happened so fast we didn't even realize that we'd lost him until after the funeral was over. Ken was one of the most loving people I've ever been privileged to know. He was keenly interested in the spiritual side of our experience and was always trying to make us see the deeper meaning of things, the value in ourselves. Not a day goes by that I don't think of him. It's still hard to accept that he's not a part of my life anymore. I believe that he would have gotten through the pneumonia, would have finished law school, if more had been known about how to treat AIDS—if more effective drugs had been available.

Eddis was diagnosed with lymphoma in January of 1987. He started radiation and chemotherapy treatments right away and his doctors said he had a better than even chance of beating it. He certainly had the right attitude, that's for sure. He just made up his mind that he was strong enough to deal with whatever came along. He responded well to the treatment at first. Then in May he developed Kaposi's Sarcoma, an AIDS-related cancer. Even then his general health was good and his spirits stayed high. His friends were shattered by the news but he kept our hopes alive and made us laugh at our own fears. Suddenly in September, he came down with pneumonia and was rushed to NYU Medical Center. He was placed on a respirator and was delirious for four weeks. Of course he couldn't talk to us and the pain killers made him so groggy that most days he couldn't even write legibly to communicate his needs. He suffered terribly then and I didn't know whether to pray for his recovery or for a release from the agony he was in. The thing none of us counted on was his incredible fighting ability. He scribbled on his pad one

day that it wasn't time for him to go yet and that we should just dig in for the duration. And he was right. After nearly ten weeks on the respirator, he was strong enough to breathe on his own again. His doctors said that they had never seen a person come through as he had. They confided in us that they never expected him to come off the respirator and certainly never to leave the hospital alive. His indomitable spirit proved everyone wrong. He recovered from the pneumonia and was released from the hospital in early December. I could see, however, during my visits with him in the ensuing weeks that his whole body was slowly falling apart. But the power of his love and acceptance and courage never wavered for a moment. He died quietly at 4:16 p.m. on Tuesday, February 23rd of this year. His last words were, 'I'm not afraid. Don't worry.' I know that had more treatments been available, Eddis would still be here sharing his lovely light in our lives. It is now 1988 and another friend is gone. I cannot accept that we have come such a little way in this fight—that since I lost Richard in July of 1984 there are still so few drugs and treatments available for AIDS.

I participated in the civil disobedience action on March 24, 1988 on Broadway and Rector Streets because I believe that if we all raise our voices loud enough and long enough, the federal health agencies and the government bureaucrats who are directing the AIDS effort will recognize that they can and *must* try harder, that the solution *can* be found if we spare no effort in finding more and better treatments for this horrible disease. I believe it is my absolute duty to bring this issue to the attention of the public, the government, the courts until such a solution is found. I must add for the record that my warrant charges me with thrashing my arms and legs while being carried to the bus by the police. That is not true. I was not there that morning to engage in physical violence of any sort. I went completely limp when the officers began to drag me away and was tossed into the bus on my head rather than even being given the option to stand and walk on board when we reached the vehicle. My neck, arms and back were badly bruised as a result.

My friends' deaths, and the deaths of the more than 34,000 others who have succumbed to AIDS, cannot and *must* not have been in vain. With the accumulated pain of so many losses, I have accepted the knowledge and the responsibility that I, as an individual, must do *everything* within my power to ensure that others will not have to endure the kind of anguish and torment that my friends did. It is the most loving tribute to their memories that I can think of.⁸⁷

V. CONCLUSION

As a lawyer, when I "accept[ed] the knowledge and responsibility that I . . . [had to] do everything within my power to ensure that others [would]

87. *Id.*

not have to endure the kind of anguish and torment that my friends did,"⁸⁸ I, naturally, looked to the law. I came to do AIDS-related legal work because I thought that such work would give me an opportunity to "control" AIDS in some way. It loomed as a constructive alternative to the constant worrying about myself, checking my body for lesions and my mouth for thrush, and about my friends, which had characterized my initial reaction to AIDS. I looked to the law as a place where I could bring some sort of order to the uncertainty and anxiety that defines my life as a gay man in the AIDS era.

In much the same way, the editors and authors and the Yale AIDS Law Project have attempted through *AIDS and the Law* to come to grips with the anxiety of the AIDS crisis. In putting together this book, they have wrestled with the social reality of AIDS and attempted to lay an organizing, legal framework onto that reality. They have done an excellent job.

Nonetheless, AIDS resists. While we empower ourselves to take control of it, and while those of us who are lawyers work through the legal system to bring order to it, AIDS continues to spread and to kill. The indeterminacy, the anxiety, and the confusion of the AIDS crisis is embodied in AIDS-related legal discourse. When seeking to order that discourse, we should not submerge AIDS' turbulence, but rather should ensure that it continues to inform our efforts.

88. *Id.*

