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FORESHADOWING FUTURE CHANGES: IMPLICATIONS OF THE AIDS PANDEMIC FOR INTERNATIONAL LAW AND POLICY OF PUBLIC HEALTH

AIDS IN THE INDUSTRIALIZED DEMOCRACIES: PASSIONS, POLITICS AND POLICIES (Ronald Bayer & David L. Kirp eds.) New Brunswick, New Jersey: Rutgers University Press, 1992. xi + 393 pp.

THE SOCIAL IMPACT OF AIDS IN THE UNITED STATES (Albert R. Jonsen & Jeff Stryker eds.) Washington, D.C.: National Academy Press, 1993. xi + 322 pp.

*Reviewed by Ilise Levy Feitshans**

INTRODUCTION

The Acquired Immune Deficiency Syndrome (AIDS)¹ has undeniably, perhaps irretrievably, changed the landscape of international public health law and policy. Ronald Bayer and David L. Kirp have noted the significant impact AIDS has had in the United States: "The right to attend school, hold a job, rent an apartment — even the rights of prisoners with AIDS not to be quarantined — have been vindicated by American courts. There are enough AIDS cases on the books to fill a thousand-page law school casebook with leading examples."²

Throughout the world, the AIDS pandemic³ has called into question traditional public health strategies such as mandatory testing, contact

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1. For the purposes of this discussion, Acquired Immune Deficiency Syndrome (AIDS) includes human immunodeficiency virus (HIV) infection, AIDS-related Complex (ARC), and certain categories of opportunistic infections, as included in the Centers for Disease Control definition of AIDS. The fluctuation in these definitions and their implications for law and clinical practice are discussed in OFFICE TECHNOLOGY ASSESSMENT, U.S. CONGRESS, OTA-BP-H-89, THE CDC'S CASE DEFINITION OF AIDS: IMPLICATIONS OF THE PROPOSED REVISIONS (1992).

2. David L. Kirp & Ronald Bayer, *Conclusion to AIDS IN THE INDUSTRIALIZED DEMOCRACIES: PASSIONS, POLITICS AND POLICIES* 361, 371 (Ronald Bayer & David L. Kirp eds., 1993).

3. "Pandemic" refers to an epidemic that transcends national borders.

tracing, and quarantine; instead it has urged public awareness of the disease and awareness of discrimination issues arising out of efforts to control AIDS. Fear of AIDS has aroused much discussion and many emotional responses,⁴ including the attempted segregation of children from the general school population,⁵ and litigation pitting surgeon against patient or surgeon against hospital for fear of transmission of the disease to⁶ or from⁷ health care providers. In employment settings, irrational fears have caused colleagues to shun and even protest working with people who have AIDS,⁸ or working with parents or partners of people with AIDS.

According to Larry Gostin, "AIDS brings with it a special stigma."⁹ In the 1980s, AIDS, ARC, and HIV seropositivity were disproportionately found to affect homosexual male populations, although as HIV spread, the demographics of the affected populations have expanded to include heterosexual men and women; presently women are considered the fastest growing risk group for HIV. The stigma of sexually transmissible diseases lay at the heart of many controversies regarding AIDS policies.¹⁰ In response to these issues, groups representing people who have AIDS, ARC, or HIV seropositivity have used their political power to bring attention to issues of discrimination in employment, insurance, and housing.

Two important books, *AIDS In The Industrialized Democracies: Passions, Politics and Policies* edited by Ronald Bayer and David Kirp

4. See, e.g., Kirp & Bayer, *supra* note 2, at 319 (discussing media reaction to Sweden's "HIV Man").

5. See *Ray v. School Dist. of DeSoto County*, 666 F. Supp. 1524 (M.D. Fla. 1987).

6. See *Miller v. Spicer*, 822 F. Supp. 158 (D. Del. 1993). A hospital denied the plaintiff immediate treatment because he was perceived to be a homosexual with HIV. The plaintiff suffered permanent damage to his foot when he was flown by helicopter from the emergency room in Delaware to a hospital in Washington, D.C., instead of receiving emergency surgery in Delaware.

7. See *Estate of Behringer v. Medical Ctr. of Princeton*, 592 A.2d 1251 (N.J. Super. Ct. Law Div. 1991) (regarding an HIV-positive surgeon); see also *Faya v. Almaraz*, 620 A.2d 327 (Md. 1993) (issue of whether an HIV-infected surgeon had a legal duty to inform patients of that condition before operating upon them, and failing that, whether a patient's fear of having contracted HIV from the infected surgeon constitutes a legally compensable injury, where the patient has not exhibited HIV infection).

8. Ilise L. Feitshans, *Confronting AIDS in the Workplace: Balancing Employment Opportunity and Occupational Health Under Existing Labor Laws*, 1989 DET. C.L. REV. 956 (1989).

9. Larry Gostin, *Hospitals, Health Care Professionals, and AIDS: The "Right to Know" the Health Status of Professionals and Patients*, 48 MD. L. REV. 12, 46 (1989), quoted in Snyder v. Mekhjian, 593 A.2d 318, 323 (N.J. 1991).

10. The role of personal responsibility for HIV infection and control of its spread is discussed in Edward A. Fallon, Note, *Preserving the Public Health: A Proposal to Quarantine Recalcitrant AIDS Carriers*, 68 B.U. L. REV. 441 (1988).

*(Industrialized Democracies)*¹¹ and *The Social Impact of AIDS in the United States* commissioned by the National Research Council (*Social Impact*)¹² catalogue several significant developments that have indelibly changed public health law and policy. The two books complement each other on any reference shelf pertaining to the AIDS pandemic. *Social Impact* provides a succinct summary of law and policy on the AIDS pandemic, including the reactions of religious groups and the special needs of women, HIV positive children, and intravenous drug users, topics rarely addressed in AIDS literature. Its findings, however, are confined to U.S. jurisdictions, with particular emphasis on two major AIDS epicenters,¹³ New York City and San Francisco. In contrast, Bayer and Kirp have succeeded in the mammoth undertaking of coordinating (and in some cases translating) AIDS articles by over sixteen experts from eleven countries.

Taken together, these books codify the existence of AIDS-related issues in the mainstream of public health law and policy by providing a coherent image of AIDS law and policy over the first decade of the pandemic. The topics covered in both books are, for the most part, the same: mandatory testing, quarantine, policy changes regarding stigma against people with AIDS in general and homosexuals in particular, and the recognition of alternative lifestyles in Western society. These issues transcend national borders and socioeconomic concerns. Therefore, this review will focus on the collective authors' treatment of three key aspects of established AIDS policy and the foreshadowing of the emerging paradigm for public health protections in the future. Part I describes the challenges to the public health care system as it faces the AIDS pandemic. Part II discusses the issues of mandatory testing, informed consent, and confidentiality of results as well as the responses of various health care systems to these issues. Part III chronicles the role of activist support groups in shaping AIDS policy in the United States and abroad. Part IV describes several discrimination issues faced by persons infected with AIDS, ARC, or HIV seropositivity. Finally, Part V explains that changes in the areas of mandatory testing, informed consent, and confidentiality exemplify global changes in public health law and policy wrought by the AIDS pandemic.

11. AIDS IN THE INDUSTRIALIZED DEMOCRACIES: PASSIONS, POLITICS AND POLICIES (Ronald Bayer & David L. Kirp eds., 1993) [hereinafter *INDUSTRIALIZED DEMOCRACIES*].

12. THE SOCIAL IMPACT OF AIDS IN THE UNITED STATES (Albert R. Jonsen & Jeff Stryker eds., 1993) [hereinafter *SOCIAL IMPACT*] (Panel on Monitoring the Social Impact of the AIDS Epidemic, sponsored by the National Research Council). Note that Ronald Bayer, an editor of *INDUSTRIALIZED DEMOCRACIES*, *supra* note 11, served on the panel of *SOCIAL IMPACT*.

13. "Epicenters" refers to epidemiological centers of disease where the most cases are located.

I. THEORETICAL ANTECEDENTS TO THE CHALLENGES POSED BY AIDS

In *Industrialized Democracies*, Bayer and Kirp document the "first wars" concerning the competing values of privacy and public health which had not previously been regarded as mutually exclusive goals.¹⁴ Following the approach taken by Bayer in his previous writing on the subject of the AIDS pandemic, *Private Acts, Social Consequences: AIDS and the Politics of Public Health* (which documented the progress of political activism in the United States surrounding the policies regarding AIDS),¹⁵ *Industrialized Democracies* illustrates the dilemmas posed by the AIDS pandemic from the perspective of eleven industrialized democracies. It serves to underscore the universality of problems posed by the AIDS pandemic, such as confidentiality of test results, the arguable rationale favoring mandatory testing, and public health policy changes that have come to the forefront of the AIDS pandemic. In this collection of well-written essays from different nations representing four continents, Bayer and Kirp primarily document political movements and some legislative changes that followed the outbreak of a pandemic that could not be ignored, even in the face of public ignorance and official denial of the existence of the disease.¹⁶

The National Research Council publication, *Social Impact*, describes the evolution of public health officials' approach to AIDS: from a doctrine of "exceptionalism" to a more mainstream acceptance of the views that were advocated to cope with the unfolding AIDS crisis.¹⁷ According to *Social Impact*, AIDS is clearly distinguishable from pretwentieth century public health concerns that regarded coercive measures as acceptable. The twentieth century's changing patterns of morbidity and mortality, effective development of clinical alternatives, and changing concepts of the police power were brought to bear on the issues raised by the AIDS pandemic. The authors note:

In some contexts, coercion is still deemed effective and justifiable from a public health perspective (e.g., laws mandating use of motorcycle helmets and automobile seat belts . . .), and elements of

14. INDUSTRIALIZED DEMOCRACIES, *supra* note 11, at 19-23.

15. RONALD BAYER, PRIVATE ACTS, SOCIAL CONSEQUENCES: AIDS AND THE POLITICS OF PUBLIC HEALTH (1989).

16. See, e.g., Eric A. Feldman & Shohei Yonemoto, *Japan: AIDS as a "Non-Issue,"* in INDUSTRIALIZED DEMOCRACIES, *supra* note 11, at 339, 356.

17. See SOCIAL IMPACT, *supra* note 12, at 7-9.

the restrictive tradition play a significant role in the assault on public smoking and the efforts to apply economic sanctions to behaviors [cigarette and alcohol consumption] deemed detrimental to public well-being, . . . *but mass persuasion is the core feature of the "new public health."*¹⁸

Just as *Industrialized Democracies* posits two "polar ideal" approaches (a "contain and control strategy" and a "cooperation and inclusion strategy"¹⁹), *Social Impact* paints a clear dichotomy between the older, "coercive" model for public health policy and the newer, "persuasive" approach to prevention in public health policy. *Social Impact* points out that even though AIDS resembles the older infectious conditions and "stigmatized sexually transmitted diseases that shaped early public health statutes and practices,"²⁰ the pandemic also resembles conditions in the "post-antibiotic era" that are linked to patterns of behavior which are "rooted in the normative structures of the communities at risk."²¹ *Social Impact* emphasizes that, by its very nature, AIDS requires the examination of public health policies from a new perspective rather than the traditional public health approach. Public health practice, however, is actually an admixture of these two approaches. *Industrialized Democracies* suggests that this false dichotomy is ultimately blended into public health practice policies in the case of AIDS, which Bayer and Kirp view as "at once viral and behavioral."²²

Social Impact views the traditional public health model as aligned with the politically conservative right. Counterpoised against those favoring the traditional approach to public health were AIDS-rights advocates seeking new, noncoercive alternatives that would balance civil liberties against the use of police power to protect public health. In Holland, policies of

18. *Id.* at 25 (citation omitted) (emphasis added).

19. Ronald Bayer & Donald L. Kirp, *Introduction* to *INDUSTRIALIZED DEMOCRACIES*, *supra* note 11, at 4-5. In describing the two types, Bayer and Kirp note:

The mix of policy decisions on AIDS adopted by any country is not reducible to single, simple formulations. Nevertheless, it seemed crucial that each case study consider the extent to which the policy components fit together to form a more or less coherent whole. We hypothesized two polar ideal types: a *contain-and-control strategy*, which would seek by compulsory means to identify those with HIV infection and then to isolate them as a way of preventing the further spread of disease; and a *cooperation-and-inclusion strategy*, which would attempt to engage those most vulnerable to AIDS through education, voluntary testing, and counseling, and by protecting their privacy and social interests as members of the commonwealth.

Id.

20. *SOCIAL IMPACT*, *supra* note 12, at 25.

21. *Id.*

22. *INDUSTRIALIZED DEMOCRACIES*, *supra* note 11, at 5.

inclusion were the cornerstone of early AIDS education, which attained public health outreach through advertisements in gay magazines and by working with the "Junkie Unions"; this fascinating chapter reveals an approach which reflects the global implications of shifting away from the coercive model in public policy.²³

Both books agree that initially AIDS was viewed as different, and therefore an "exceptionalist" approach (which favored a modern understanding of privacy, individual rights, and civil liberties over the more traditional "coercive" approach) dominated AIDS policy.²⁴ *Social Impact*, however, also makes the important and often forgotten point that the AIDS pandemic merely catalyzed the developments that were beginning to appear in public health. The older approach increasingly came to be viewed as antithetical to civil liberties, as it posed the specter of quarantine, partner notification, contact tracing, mandatory testing, registries, mandatory reporting, mandatory testing for pregnant women as "vectors" of disease, and mandatory newborn screening — all without informed consent.²⁵ AIDS activism brought an adjustment of these traditional "authoritarian measures"²⁶ to meet the new challenges for public health policy.

II. MANDATORY TESTING, INFORMED CONSENT, AND CONFIDENTIALITY OF TEST RESULTS

Nowhere has the influence of advocacy groups for people with AIDS been more distinctive than in the area of mandatory testing and confidentiality of test results.²⁷ In the past, the traditional public health model

23. Jan K. van Wijngaarden, *The Netherlands: AIDS in a Consensual Society*, in INDUSTRIALIZED DEMOCRACIES, *supra* note 11, at 252, 260–61.

24. SOCIAL IMPACT, *supra* note 12, at 26; Ronald Bayer & David L. Kirp, *The United States: At the Center of the Storm*, in INDUSTRIALIZED DEMOCRACIES, *supra* note 11, at 7, 8.

25. The National Research Council Panel notes:

Education, it was broadly agreed, had to be the centerpiece of the effort . . . Testing for HIV infection was to be undertaken only after obtaining the informed consent of those to be tested. The tradition of compulsory or routine mass public screening in the face of epidemic threats was rejected. The reporting of those with HIV infection to public health registries was to be avoided because it might discourage individuals from voluntarily coming forward for HIV testing. Confidentiality of HIV-related medical records was to be rigorously protected, sometimes at the cost of warning intimates who could unknowingly be subjected to the threat of infection. The use of the power of quarantine was to be avoided even when it was found that in specific cases an individual was behaving in ways that posed the threat of infection to others.

SOCIAL IMPACT, *supra* note 12, at 26–27.

26. Bayer & Kirp, *supra* note 24, at 9.

27. SOCIAL IMPACT, *supra* note 12, at 27 ("No issue has consumed more attention in the controversies over public policy and AIDS than the use of the antibody test to identify people infected with HIV.").

implemented mandatory measures to help determine the seroprevalence of disease and established disease registries to follow up on the progress of people with the disease; the traditional model also made broader policy assessments regarding the course of official actions.

One of the initial concerns about mandatory testing involved the exposure of people with AIDS to stigma and discrimination. Another concern involved the involuntary quarantine of people with AIDS, which activists viewed as a draconian measure but which remains an important public health tool for recalcitrant people with tuberculosis.²⁸ In Britain,²⁹ compulsory screening was demanded in Parliament as recently as 1986.³⁰ In Spain, the director of Spain's AIDS research proposed quarantine for everyone with the virus.³¹ These views expressing concerns about HIV-infected people who have tested positive and seroconverted are also reflected in articles about involuntary control measures for recalcitrants in the United States.³² Quarantine, however, is not the accepted approach. As de Miguel and Kirp noted, if quarantine "were ever to become policy it would turn Spain into another Cuba, the only nation that isolates its HIV-infected population," which underscores the current inappropriateness of the coercive public health model.³³

On its face, the coercive approach could be justified as a means to measure the incidence of HIV infection, because mandatory testing is an efficient method to establish public health databases to analyze prevalence and follow upon affected populations. But the establishment of a database is exactly one measure that AIDS activists, fearing stigma on many social levels, sought to avoid. In the case of AIDS, the mandatory approach yielded to a new overarching concern for patient confidentiality and the desire to encourage people to accept treatment rather than to go "underground." Bayer and Kirp state that because AIDS was recognized in many industrialized nations, these concerns surfaced early in the pandemic.³⁴

28. See, e.g., Stephen C. Joseph, *Quarantine: Sometimes a Duty*, N.Y. TIMES, Feb. 10, 1990, at A25 (discussion by former Commissioner of Health for New York City). Dr. Joseph stated that, "When all lesser remedies have failed, can anyone doubt what would be the proper course of action for the Commissioner to take, faced with . . . an infected individual who knowingly and repeatedly sold his blood for transfusion." *Id.*

29. John Street & Albert Weale, *Britain: Policy Making in a Hermetically Sealed System*, in INDUSTRIALIZED DEMOCRACIES, *supra* note 11, at 185, 192.

30. *Id.* at 200.

31. Jesus M. de Miguel & David L. Kirp, *Spain: An Epidemic of Denial*, in INDUSTRIALIZED DEMOCRACIES, *supra* note 11, at 168.

32. See, e.g., Fallon, *supra* note 10.

33. de Miguel & Kirp, *supra* note 31, at 169.

34. See Bayer & Kirp, *supra* note 19, at 3-4.

In addition to demanding confidentiality in public health programming, groups representing people who have AIDS, ARC, or HIV seropositivity have changed the public health agenda regarding informed consent in general and for blood tests in particular. Concerns for the psychological import of taking a test to determine the presence or absence of HIV infection,³⁵ combined with a desire to preserve patient autonomy, soon surfaced and confronted policymakers. *Social Impact* notes that “[t]he Institute of Medicine in its recent report, stressed the urgency of identifying infected children, but came out strongly against imposing testing on women and children.”³⁶ For these reasons, voluntary testing with informed consent after counseling became the centerpiece of several public health initiatives in the first decade of the AIDS pandemic. According to *Industrialized Democracies*:

To assure that testing would in fact be voluntary, some states enacted statutes requiring that written specific consent be obtained before testing occurred. The insistence on such rigor stood in marked contrast to the standard American practice in medicine, where consent to diagnostic blood tests is assumed once an individual has come for treatment. *To many clinicians, the demand for specific consent represented a burdensome intrusion into the practice of medicine.*³⁷

Additionally, *Social Impact* notes that in U.S. prisons, the presence of AIDS, ARC, and HIV seropositivity has generated new policies — in some cases resulting in the segregation of affected prisoners.³⁸ Both books demonstrate that, in general, counseling became a mandatory precondition to HIV testing and to the posttest disclosure of results. Consistent with the view of advocates for people with AIDS, but not commented upon by either book, Larry Gostin and William J. Curran have assailed mandatory HIV testing and supported voluntary, confidential testing in all but rare instances.³⁹ Larry Gostin and William J. Curran suggest that criteria

35. van Wijngaarden, *supra* note 23, at 264. (“Members of the Coordinating Team were aware of reports from the United States about potentially catastrophic consequences of being told that one had tested positive for the antibody to HIV. Thus, . . . a campaign was undertaken to urge gay men to think twice before undergoing testing.”).

36. SOCIAL IMPACT, *supra* note 12, at 215.

37. Bayer & Kirp, *supra* note 24, at 27 (emphasis added).

38. SOCIAL IMPACT, *supra* note 12, at 187. This study notes that “[a]t least 20 state prisons segregate all prisoners with AIDS; 8 segregate those with AIDS-related complex; and 6 segregate inmates who are HIV positive but not symptomatic. . . . Courts have thus far rejected efforts to either compel or stop the segregation of prisoners with HIV disease.” *Id.*

39. Larry Gostin & William J. Curran, *AIDS Screening, Confidentiality, and the Duty to Warn*, 77 AM. J. PUB. HEALTH 361–62 (1987). Gostin and Curran’s criteria for determining

regarding mandatory testing for AIDS may only be developed under extremely limited circumstances. France provided one surprising exception to these policies by requiring mandatory reporting, which was used to develop epidemiological information within the context of a universal health care system that provided one-hundred percent coverage for AIDS patients.⁴⁰

AIDS therefore has set a precedent for informed consent and counseling prior to testing (with the right to refuse testing) and detailed discussion of test results, which was not previously indicated for tests such as a "routine" blood test. This is contrary to the usual medical practice for blood tests, because blood tests are not ordinarily considered sufficiently invasive to merit counseling before obtaining results. Informed consent for HIV blood tests has resulted in a shift away from an inquiry into the "invasiveness" of a test or procedure and towards a focus on the importance or emotional impact of information derived from the test as a determinant of the need for pretest and posttest counseling and informed consent for testing. Thus, in response to the disfavor of mandatory testing during the AIDS crisis, an elaborate structure for anonymous, confidential testing has been created with pretest and posttest counseling to ensure that people have given informed consent and that they understand test results. This modification of the public health model may affect public health policy in the future in other areas of testing regarding emotionally laden but informative blood tests.

The new approach developed in response to AIDS may have implications for other areas of public health where the results of a blood test bear great emotional freight, such as genetics. For example, in the Institute of Medicine Report, *Assessing Genetic Risks: Implications for Health and Social Policy (Assessing Genetic Risks)*, the National Academy of Sciences Institute of Medicine describes a possible future form of prenatal diagnosis, where a mother's blood may be drawn to reveal the genetic composition of fetal cells found in maternal serum.⁴¹ Such blood tests

whether there is a justification for mandatory testing for purposes of public health programs can be summarized as follows: (1) the selected population should have a reservoir of infection to avoid disproportionate numbers of infected persons having to submit to intrusive testing procedures; (2) there must be a significant risk of communication of the infection; (3) test results should enable authorities to take precautions and reduce the threat of infection; (4) critical consequences of testing should not outweigh the benefits; and (5) no less intrusive means of achieving the public health objective are available. *Id.*

40. Monika Steffen, *France: Social Solidarity and Scientific Expertise, in INDUSTRIALIZED DEMOCRACIES*, *supra* note 11, at 221, 227.

41. ASSESSING GENETIC RISKS: IMPLICATIONS FOR HEALTH AND SOCIAL POLICY, at ch. 2, at 19 (Lori B. Andrews et al. eds., forthcoming 1994) [hereinafter ASSESSING GENETIC RISKS] (November 1993 prepublication copy of Institute of Medicine report).

could reveal information about inherited disease in a given fetus, which may be as emotionally charged as an HIV test result. Mindful of this potential, *Assessing Genetic Risks* urges increased genetic counseling before and after genetic testing and expresses profound concern for the rights of people who may be subject to testing. The Committee disfavors mandatory prenatal testing. As repeated in the final segment of the report, the Executive summary of *Assessing Genetic Risks* states: "Voluntariness should be the cornerstone of any genetic testing program."⁴² Although the Committee does not so state, this approach is consistent with the new public health paradigm that has emerged since the AIDS pandemic. Thus, political pressure surrounding HIV infection has generated a reevaluation of otherwise widely accepted public health strategies that require mandatory testing.

III. POLITICAL ACTIVISM SHAPING THE FORMULATION OF AIDS POLICY

Change is the theme that best summarizes the outcome of political activities surrounding AIDS, as described by both books. Australian members of the AIDS Action Committee lobbied for setting clinical criteria and defining cases of AIDS.⁴³ In Canada, political pressure was applied to secure access to untested zidovudine (AZT)⁴⁴ under the Emergency Drug Release Program,⁴⁵ and used to develop a multilevel approach to achieve a coherent national AIDS policy⁴⁶ so that federal, provincial, and local levels of government were forced to address these issues.⁴⁷ Canadian activists challenged the traditional approach to public health,⁴⁸ but physicians also played a key role in the development of increased awareness and funding regarding AIDS.⁴⁹ In Denmark, "policy choices have, from the very start, been owned almost exclusively by a political alliance consisting of medical professionals and various groups perceived as being at risk of contracting AIDS, most notably gay men."⁵⁰

42. *Id.* at 18.

43. John Ballard, *Australia: Participation and Innovation in a Federal System*, in INDUSTRIALIZED DEMOCRACIES, *supra* note 11, at 134, 139.

44. SOCIAL IMPACT, *supra* note 12, at 52.

45. David M. Rayside & Evert A. Lindquist, *Canada: Community Activism, Federalism and the New Politics of Disease*, in INDUSTRIALIZED DEMOCRACIES, *supra* note 11, at 49, 87.

46. *Id.* at 88.

47. *Id.* at 91.

48. *Id.* at 83.

49. *Id.* at 85.

50. Eric Albaek, *Denmark: AIDS and the Political "Pink Triangle,"* in INDUSTRIALIZED DEMOCRACIES, *supra* note 11, at 281, 282.

As examples of policy changes in epicenters, both books focus attention on activities in New York and San Francisco. *Social Impact* describes how activists in New York City fought against a quarantine policy, favoring instead the development of anonymous test centers with counseling. *Social Impact* also provides detailed accounts of the political activity surrounding two referenda in San Francisco that legitimized same-sex marriages. Quoting campaign literature for one referendum, *Social Impact* states, "Your partner dies — and you don't even have the right to leave work for the funeral."⁵¹ *Social Impact's* narrative captures the essence of the campaign's emotional appeal to promoting stability through same-sex marriages. Religious overtones, which are not addressed in the chapter concerning the reaction by organized religions, are also touched upon in this unusual and insightful chapter. Such concerns apparently did not come to the forefront when same-sex marriages became legal in Denmark in 1989.⁵² *Social Impact's* chapter on religion provides a comparatively tame exposition of the official statements of organized religious institutions. Without depicting the condemning rhetoric that was the hallmark of many religious leaders at the start of the pandemic (such as Guenter Frankenberg's statement in Germany that "AIDS has been characterized as God's punishment"⁵³), *Social Impact* calmly describes organized religious reactions to people with AIDS as contrasted with the inflammatory rhetoric of congregants who "rejected the idea of sharing the cost of providing [health insurance] benefits for people whose sexual behavior they abhorred."⁵⁴

Despite its global approach, *Industrialized Democracies* does not discuss religion extensively. It also remains deliberately distant from issues of economic equality among nations, although it does touch upon the role of economics with regard to equal access to medical care in the United States. Several chapters echo Bayer and Kirp's theme that "the United States assumed center stage,"⁵⁵ and they name the chapter on the United States "At the Center of the Storm." Bayer and Kirp view the U.S. experience with AIDS as the model for both what to do and what not to do in the face of an AIDS epidemic in a given nation. One is immediately tempted to question the validity of this approach — asking whether this

51. SOCIAL IMPACT, *supra* note 12, at 225.

52. Alback, *supra* note 50, at 285.

53. Guenter Frankenberg, *Germany: The Uneasy Triumph of Pragmatism*, in INDUSTRIALIZED DEMOCRACIES, *supra* note 11, at 99, 113.

54. SOCIAL IMPACT, *supra* note 12, at 224. This comment was made in relation to the campaign for legitimization of same-sex marriages, but should have been included in the chapter concerning religion.

55. Bayer & Kirp, *supra* note 19, at 2.

is merely a neat analytical tool for use by two U.S.-based writers. They do provide a persuasive case, however, by presenting the United States first as a model case. This point is amplified by the many foreign references to Rock Hudson and other victims of the U.S. epidemic in the discussion by authors from other nations. Germany considered AIDS the "American Disease,"⁵⁶ and the Australian media announced AIDS as "U.S. Killer Disease Reaches Australia."⁵⁷ In Sweden, gay physicians founded the Noah's Ark Foundation, "loosely patterned after New York City's Gay Men's Health Crisis," which demonstrates the United States' potential to provide a positive influence.⁵⁸

Bayer and Kirp justify their conscious decision not to discuss poorer nations, such as those in Africa where there is an equally unique and dangerous threat of AIDS, by focusing on different national cultures of similar economic levels, combined with their stated desire to glean lessons that can be drawn from the experiences of different countries.⁵⁹ AIDS law and policy is not a monolith. Bayer and Kirp seek to learn from cultural differences across eleven nations. Nonetheless an image quickly emerges of remarkable similarities, perhaps even a universality, of policy approaches despite differences in cultures.

Bayer and Kirp have printed their suggested framework for essays by contributors in the Introduction, but the issues that they suggest are not consistently considered from one chapter to the next and not governed by any particular order. Consequently, there is much valuable information in this work that is not readily apparent on the first reading, which slightly impedes its usefulness as an information resource. This makes access more difficult for those people interested in using this as a reference work, but makes for better writing; each chapter is extremely well written and can stand alone — maintaining the flavor of different authors' styles.

56. Frankenberg, *supra* note 53, at 99.

57. Ballard, *supra* note 43, at 138.

58. Benny Henriksson & Hasse Ytterberg, *Sweden: The Power of the Moral(istic) Left*, in *INDUSTRIALIZED DEMOCRACIES*, *supra* note 11, at 317, 322.

59. Bayer & Kirp, *supra* note 19, at 2. The editors state that:

By restricting our focus to economically advanced democracies, we can see how differing national cultures have affected the response to AIDS and have shaped the experience of the epidemic, even when embedded in economic systems able to provide decent (if not always equitable) health care and in political systems that share a commitment to liberal democratic values. We can also examine the prospects for countries to learn from one another.

IV. DISCRIMINATION IN INSURANCE AND EMPLOYMENT

Without question, concern for loss of jobs, insurance and housing is synonymous with the AIDS pandemic.⁶⁰ Astronomically high costs of medical care combined with social stigma against people with AIDS rapidly emerged as barriers preventing access to health care. One of the early rallying cries of AIDS activists has been the battle against stigma associated with risk groups and the presence of the disease. As in the case of many other diseases that are the subject of ongoing research, treatments may cause insurers or self-insured employers to incur great financial expense. Therefore, employers and their insurers have significant financial incentives to remove affected populations and asymptomatic carriers from insurance risk pools for employment-based health or life insurance. Discrimination law and antidiscrimination policies therefore constitute a major area of common concern in the AIDS pandemic.

Throughout the world, as in the United States, combating fears and economic issues necessitates activities on legal and public health fronts.⁶¹ In Japan, social stigma has taken the form of having "AIDS" written on school children's belongings.⁶² In contrast, antidiscrimination legislation was passed in Australia regarding sexual preference,⁶³ but lobbying was unsuccessful in the United Kingdom to prevent life insurance discrimination.⁶⁴ Bayer and Kirp⁶⁵ discuss popular fear in the United States as it gave rise to the need for litigation concerning admission of children with AIDS into public schools,⁶⁶ and they cite a survey by the American Civil Liberties Union that found more than 13,000 complaints of HIV-related discrimination between 1983 and 1988, with a substantial increase in the later years.

Although there have been major legislative initiatives in the United States prohibiting discrimination against people with AIDS, ARC, or HIV seropositivity, neither book gives this topic more than peripheral attention. Surprisingly, neither book provides detailed analysis of new AIDS-related legislation and legal decisions, such as the Americans With Disabilities

60. See SOCIAL IMPACT, *supra* note 12, at 18-21.

61. Bayer & Kirp, *supra* note 24, at 17.

62. Yonemoto, *supra* note 16, at 353-54 ("Many adult hemophiliacs have been required by employers to show copies of HIV test results, have had to change jobs, and have been shunned by neighbors.").

63. Ballard, *supra* note 43, at 137. Note, these were local laws, not federal legislation.

64. Street & Weale, *supra* note 29, at 212.

65. Bayer & Kirp, *supra* note 24, at 19.

66. *Id.* at 15.

Act of 1990 (ADA) in the United States,⁶⁷ which has brought sweeping changes. It would have been interesting if greater attention had been paid to the role of AIDS activism in successfully achieving these important legislative goals.

V. FORESHADOWING THE FUTURE

One consequence of the turmoil that surrounds attempts to address the issues raised by AIDS has been the large-scale questioning of the validity of mandatory screening and testing in light of the potential harm of economic loss or discrimination against people who have been tested. These important questions hold implications for other mandatory screening programs affecting public health. For example, concern for the coercive implications of mandatory screening was evinced in *Assessing Genetic Risks*, which discusses the rights of pregnant women to obtain or refuse prenatal diagnosis for genetic diseases. *Assessing Genetic Risks* opposes mandatory genetic testing. Although the report does not mention AIDS, ARC, or HIV seropositivity as its theoretical antecedents, there are striking similarities of language and approach found in the discussions of mandatory newborn screening with AIDS testing strategies and their implications for public health.

In cases of genetic discrimination, *Assessing Genetic Risks* expresses concerns that employment and insurance discrimination against people with genetic disabilities may affect the insurability and health status of families and dependents in much the same manner that early AIDS case law reflected a concern for family members with AIDS. Not only the concerns for discrimination issues, but also the mechanisms for framing the issues, clearly follow the emerging AIDS paradigm. Thus, the AIDS pandemic has created a sensitivity to issues surrounding insurance discrimination — with resulting changes in the patterns of data collection and a heightened concern for confidentiality in the use and dissemination to the public of all types of health data.⁶⁸ Similar issues regarding privacy, confidentiality, mandatory testing, and protection against discrimination in insurance and employment have been raised in the context of genetic discoveries in the wake of the human genome project. The significance of these developments as manifested by the AIDS pandemic is underscored by *Assessing Genetic Risks*, which is based on the startling premise

67. 42 U.S.C. § 12101–213 (Supp. III 1991).

68. *Estate of Behringer v. Medical Center of Princeton*, 592 A.2d 1251 (N.J. Super. Law Div. 1991), concerned a surgeon who became an AIDS patient in the hospital where he worked. The concern that the hospital had breached confidentiality by making his condition known to staff, who in turn notified his patients, was a seminal feature of this complicated case.

that the traditional public health model is inappropriate in the genetics context.⁶⁹ In the case of genetic diseases, mandatory testing has been criticized as a potential tool for eugenics by enabling the State to filter out undesirable genetic traits through obligatory testing.⁷⁰ These critics clearly rely on the AIDS precedent for their view that informed consent, as a part of pretest and posttest counseling, should be required for all genetic testing. The outcome of these policy issues remains to be determined, but it is already clear that the resolution of these important issues has been shaped in part by experience with the AIDS pandemic.

CONCLUSION

As Bayer and Kirp note, “[p]ublic policy on AIDS has begun to undergo a profound transformation.”⁷¹ Public policy debates raised by AIDS followed by major changes in public health strategy in the late twentieth century exemplify such a switch in public policy. These changes brought about the reexamination of rights to privacy in the context of major intimate personal decisions, behavioral decisions, and responsibilities in the most intimate sexual contexts. Pressured by unusually strong activism from the affected population, programs that combat AIDS have aggressively sought funding for medical care, research, and public education campaigns. AIDS activists have fought for faster clinical trials for new drugs and experimental uses of drugs for people with HIV infection. Additionally, there have been successful campaigns to pass laws prohibiting discrimination against people with AIDS, ARC, or HIV seropositivity to ensure continuing health and life insurance coverage and to protect the confidentiality of HIV-related information in a manner that is unlike the flow of information regarding other diseases. Yet, much remains to be done. For example, there is an absence of clear legislation governing a physician’s duties regarding the disclosure of HIV test results. Needle exchange and safer sex policies remain controversial; mass media

69. Regarding Public Health Education, the Institute of Medicine Committee on Assessing Genetic Risks stated:

The goal of health education interventions is to prevent disease and promote health. A traditional public health model is to define the problem, identify risk factors, develop and test interventions, implement these interventions, evaluate promotion effectiveness, and develop a national program. . . . [This model] could also mistakenly encourage the public to believe that screening or genetics knowledge will make the outcome of every pregnancy a perfectly healthy baby, eliminate all disease, or make everyone “normal.”

ASSESSING GENETIC RISKS, *supra* note 41, ch. 5, at 9.

70. See generally TROY DUSTER, BACK DOOR TO EUGENICS 124–29 (1990).

71. Bayer & Kirp, *supra* note 24, at 43.

campaigns directed at behavioral change for prevention of HIV infection must continue. More work is needed in these regards, but these two books chronicle results already achieved, documenting changes in public health law and policy as crystallized by the AIDS pandemic.