

## **AIDS Law - Past and Future**

### **Testimony before the Presidential Advisory Council on HIV/AIDS: AIDS Law - Past and Future 21 June 2005**

Revised - 22 June 2005

Edward P. Richards

Director, Program in Law, Science, and Public Health

Harvey A. Peltier Professor of Law

Paul M. Hebert Law Center

Louisiana State University

Baton Rouge, LA 70803-1000

richards@lsu.edu

<http://biotech.law.lsu.edu>

For more information and the final presentation, see:

<http://biotech.law.lsu.edu/cphl/slides/aids-com.htm>

### **A Public Health Law History**

#### **A.1 The Roots of Public Health**

A.1.1 Leviticus

A.1.2 Roman water and sewer works

A.1.3 Early Renaissance Venice

    A.1.3.1 quadraginta

A.1.4 Blackstone

    A.1.4.1 Death for breaking quarantine

#### **A.2 Public Health in the Colonies**

A.2.1 Most of the population lived in poorly drained coastal areas

    A.2.1.1 Cholera

    A.2.1.2 Yellow Fever

A.2.2 Urban Diseases

    A.2.2.1 Smallpox

    A.2.2.2 Tuberculosis

A.2.3 Average life expectancy was short

### A.3 Public Health Law Actions in Colonial America

A.3.1 Quarantines, areas of non-intercourse

A.3.2 Inspection of ships and sailors

A.3.3 Nuisance abatement

A.3.4 Colonial governments had and used Draconian public health powers

A.3.4.1 The Police Powers

### A.4 Public Health in the Constitution

A.4.1 Federal Powers

A.4.1.1 Interstate commerce

A.4.1.2 International trade and travel

A.4.1.3 War

A.4.2 State Powers

A.4.2.1 Powers not given to the federal government

A.4.2.2 Police Powers

A.4.2.3 All public health except that related to foreign shipping and commerce

### A.5 Public Health: 1850 - 1965

A.5.1 Sanitation

A.5.1.1 Drinking water

A.5.1.2 Waste water

A.5.2 Environmental Health

A.5.2.1 Food inspection

A.5.2.2 Housing codes

A.5.2.3 Working conditions

A.5.3 Communicable Diseases

A.5.3.1 Vaccinations

A.5.3.2 Investigation and control

### A.6 Communicable Disease Investigation and Control

A.6.1 Mandatory reporting of cases

A.6.1.1 By name

A.6.1.2 No anonymous testing

A.6.2 Disease investigation

    A.6.2.1 Contact tracing

    A.6.2.2 Tuberculosis screening

A.6.3 Disease interventions

    A.6.3.1 Contact ("Partner") notification

    A.6.3.2 Mandatory treatment

    A.6.3.3 Isolation and quarantine

A.7 Public Health Law

A.7.1 Best public health practices shaped public health law

A.7.2 The courts uniformly supported public health laws

A.7.3 Public health laws and public health departments had broad public support

A.7.4 The last public health law practice guide was published in 1949.

Tobey, Public Health Law (3rd Edition), The Commonwealth Fund, New York, 1947 <http://biotech.law.lsu.edu/cphl/history/books/tobey/tobey.htm>

A.8 The Results - 1850 - 1965

A.8.1 Urban life expectancy more than doubled between 1850 and 1950

A.8.2 Urban and rural life expectancy converged

A.8.3 Infant mortality dropped dramatically

A.9 Public Health in 1965

A.9.1 Tuberculosis is under control

A.9.2 Food and water borne diseases are rare

A.9.3 Yellow fever, malaria, and smallpox are eradicated in the US

A.9.4 Polio is under control

A.9.5 Vaccinations are routine and not controversial

## B Leading up to AIDS: 1965 - 1980

B.1 The demise of communicable diseases as a concern in the US

B.1.1 Tuberculosis treatment reduces the need for isolation

B.1.2 Polio vaccine

B.1.3 Smallpox is eradicated in the US

B.1.4 Bacterial illnesses were susceptible to common antibiotics

B.1.5 In 1969 U.S. Surgeon General William H. Stewart testified before Congress  
that it was time to close the book on infectious disease.

## B.2 Successful Public Health Destroys Public Support for Public Health

### B.3 The Role of Fear in Public Health

B.3.1 "Reasonable fear saves many lives and prevents much sickness. It is one of the greatest forces for good in preventive medicine, as we shall presently see, and at times it is the most useful instrument in the hands of the sanitarian."

M. J. Rosenau, The Uses Of Fear In Preventive Medicine, Boston Medical and Surgical Journal, Vol. 162, #10, 305 - 307, Mar. 10, 1910  
[http://biotech.law.lsu.edu/cphl/history/articles/Rosenau\\_fear.htm](http://biotech.law.lsu.edu/cphl/history/articles/Rosenau_fear.htm)

### B.4 Medicaid and the Great Society

B.4.1 Created a huge fund for indigent medical care

B.4.2 Important focus on prenatal and pediatric care

B.4.3 Transformed many health departments into medical care providers

B.4.4 Personal medical care expertise displaced public health expertise

### B.5 Vaccine liability cases

B.5.1 Cutter Incident - 1955

B.5.2 Restatement of Torts 2nd - 1965

B.5.2.1 Created strict liability

B.5.2.2 Exception for drugs only covers risks the doctor/patient was warned of

B.5.2.3 Allows liability for unforeseeable risks

B.5.2.4 Allows alternative design claims

B.5.3 Fueled Anti-vaccine campaigns by plaintiff's lawyers

### B.6 Stonewall Riots - 1969

B.6.1 Focused public attention on police harassment of gay men and women

B.6.2 Showed the political power of gay voters and supporters in big cities

B.6.3 Made the newly emerging bathhouse culture off limits to public health enforcement

## B.7 Tuskegee Syphilis Experiment

B.7.1 B.7.1 The presentation and the briefing book outline did not touch on the Tuskegee Syphilis Experiment, which was brought to light in the late 1960s and was investigated in the early 1970s. This experiment began in the 1930s to study the natural history of untreated syphilis in black men. It was continued until the late 1960s, long after penicillin became available (1945), making syphilis treatment safe and effective. This study did great harm to the participants, and to their wives and partners and children, who were also infected during the duration of the experiment. It undermined the credibility of the public health establishment in minority communities and created suspicion of all public health programs targeting minorities. This suspicion continues to complicate HIV control programs in minority communities and must be addressed as new initiatives are developed to deal with the epidemic of HIV in these communities.

FINAL REPORT of the Tuskegee Syphilis Study Ad Hoc Advisory Panel,  
HEW (1973)

<http://biotech.law.lsu.edu/cphl/history/reports/tuskegee/tuskegee.htm>

## B.8 Swine Flu - 1976

B.8.1 Driven by the real fear of a global flu pandemic

B.8.2 Vaccine was rushed into production

B.8.3 A national compensation program was set up

B.8.4 Massive push to vaccine the public

B.8.5 No cases of Swine Flu

## B.9 Swine Flu - The Epilog

B.9.1 Fear of Guillain-Barre syndrome lead to over diagnosis.

D.A. Freedman & Philip B. Stark, The Swine Flu Vaccine and Guillain-Barré Syndrome: A Case Study in Relative Risk and Specific Causation, 23 Evaluation Review 619 (1999)

B.9.2 Lawyers helped patients find sympathetic docs

B.9.3 Huge liability for the government, despite limited scientific support.

Unthank v. United States, 732 F.2d 1517 (10th Cir. 1984)

<http://biotech.law.lsu.edu/cases/vaccines/Unthank.htm>

## B.10 Hepatitis B in the Bathhouses

B.10.1 Data published in 1976 and 1977 showed a huge hepatitis B epidemic in the bathhouses

B.10.2 Almost everyone who was active became infected

B.10.3 Hepatitis B is sometimes fatal, with long term complications

B.10.4 Nothing was done to close the bathhouses

B.10.5 Why?

## B.11 Bathhouses and HIV

B.11.1 HIV was rare initially

B.11.1.1 Bathhouses allow a huge number of different contacts

B.11.1.2 Bathhouses allow mixing of social classes and nationalities

B.11.2 HIV is hard to catch

B.11.2.1 Bathhouses allow high frequency sex

B.11.2.2 Bathhouses allow high risk sex

B.11.2.3 HIV is also spread through IV drug use, which was also present in some bathhouse patrons

B.11.3 Without bathhouses, HIV would be a small problem in the US

B.11.3.1 Mathematical models show that bathhouses amplified the HIV epidemic in gay men

B.11.3.2 Models show that bathhouses are still critical to the spread of HIV in the US

James R. Thompson, Is the United States Country Zero for the First-World AIDS Epidemic?" (2000) {The Journal of Theoretical Biology}, pp. 621-628; and

James R. Thompson, Understanding the AIDS Epidemic: A Modeler's Odyssey" (1999), in Mathematical Modeling, D. Shier and T. Wallenius, eds., New York: CRC Press pp. 41-69.

<http://biotech.law.lsu.edu/cphl/Models/index.htm>

## C AIDS and the Aftermath

### C.1 1981 - Ground Zero in the United States

C.1.1 GRID and the first cases

C.1.1.1 HIV was originally concentrated in several metropolitan areas on the coasts: San Francisco, Los Angeles, Houston, Miami, and in the East Coast Metroplex from Baltimore through Washington DC, New Jersey, New York City to Boston.

C.1.2 Working out the epidemiology

C.1.2.1 We did traditional investigation for the first cases

C.1.2.2 Exactly the same epidemiology as the hepatitis B in the bathhouses in the

1970s

C.1.2.3 Exactly the same people

C.1.2.4 Shilts, Randy: And the Band Played On (New York: St. Martin's Press, 1987) (not the movie)

C.1.3 The bathhouses redux

C.1.3.1 Some public health experts pushed to close the bathhouses, and lost their jobs

C.1.3.2 Gay activists and bathhouses owners claimed that bathhouses were good places to do sex education

C.1.3.3 Bathhouses were left open until 1985, when death weakened the opposition to closing

City of New York v New St. Mark's Baths, 130 Misc. 2d 911, 497 N.Y.S.2d 979 (1986)

[http://biotech.law.lsu.edu/cases/STDs/St\\_marks\\_I.htm](http://biotech.law.lsu.edu/cases/STDs/St_marks_I.htm)

C.2 Initial Fears

C.2.1 When it was known that AIDS was a disease of gay men and IV drug users, questions were raised about whether it could be spread to others

C.2.1.1 Pressure to fire gay waiters and hair dressers

C.2.1.2 Claims of housing discrimination against persons with AIDS

C.2.1.3 These claims were difficult to substantiate

C.2.1.4 Association of State and Territorial Health Officers, Guide to Public Health Practice: AIDS Confidentiality and Anti-Discrimination Principles (March 1988)[

C.2.2 The Response

C.2.2.1 Civil libertarians pushed to keep information about AIDS secret

C.2.2.2 Blood banks, for their own reasons, declined to eliminate donations by gay men and IV drug users

C.2.2.3 AIDS was still reportable because you had to be identified to get government benefits

C.3 The HIV Test

C.3.1 In 1985 a blood test for HIV became available

C.3.1.1 The debate shifted to the identification of HIV carriers who had not yet developed AIDS

C.3.1.1.1 Some states required reporting positive HIV tests by name, as with other diseases such as syphilis Rothenberg R, Bross D, and Vernon T,

Reporting of Gonorrhea by Private Physicians: A Behavioral Study, 70 Am. J. Pub. Health 983 (1980)

C.3.1.1.2 Colorado passed the first HIV reporting law

Edward P. Richards, "Communicable Disease Control in Colorado: A Rational Approach to AIDS," 65 U. Dev. L. R. 127-179 (1988)  
[http://biotech.lsu.edu/cphl/articles/CO\\_HIV.pdf](http://biotech.lsu.edu/cphl/articles/CO_HIV.pdf)

C.3.1.2 None of the states with high numbers of AIDS cases required HIV to be reported

C.3.1.2.1 It was argued that the only reason to report was to get people treated.

C.3.1.2.2 This ignored the role of reporting for epidemiology and for other disease control measures, as done for other untreatable diseases.

C.3.1.2.3 The federal government did not require mandatory name reporting as a condition for federal AIDS funds.

C.3.2 Anonymous testing

C.3.2.1 The radical departure from traditional disease control came with the advent of anonymous testing

C.3.2.2 Health departments had always had a few people give fake names in sexually transmitted disease (STD) clinics, but the clinic policies did not encourage this

C.3.2.3 Test sites were established where all testing was anonymous, which prevented reporting and investigation

C.3.3 The Federal Role in Anonymous Testing

C.3.3.1 Congress was lobbied to require anonymous testing sites as a condition of federal funding

C.3.3.2 Public health experts, most of whom worked for government agencies, could not lobby congress in opposition

C.3.3.3 States with named reporting were forced to allow anonymous testing

C.3.4 Anonymous Testing Today

C.3.4.1 There is no evidence that anonymous testing has a significant effect on HIV testing

Judson F. and Vernon T., The Impact of AIDS and HIV on State and Local Health Department, 78 Am. J. Pub. Health 387 (1988).

C.3.4.2 Anonymous testing hobbles all subsequent disease control efforts

C.3.4.3 Anonymous testing is still offered in all states

C.4 The National Reporting System

C.4.1 All disease reporting is local, with data sent to the state, and from the state to the federal government.

- C.4.2 There are no national standards for disease control data reporting and no national reporting laws for communicable diseases.
- C.4.3 Most disease control data that is reported to federal government does not contain personal identifying information so there is no national database on HIV or most other communicable diseases.
- C.4.4 Since travel plays a significant role in HIV transmission, it is important to have a good national database.
- C.4.5 Such national data does exist for AIDS, since many AIDS patients get care through the Social Security Disability system, but that data is not used for disease control.

## C.5 Disease Investigation

### C.5.1 Contact Tracing

- C.5.1.1 Many states do not do contact tracing because they see it as an invasion of privacy
- C.5.1.2 It also requires named reporting and no anonymous testing to get good input data.
- C.5.1.3 It does not require perfect reporting because overlapping contacts help fill in missing data.  
Herbert W. Hethcote and James A. Yorke, Gonorrhea Transmission Dynamics and Control, Springer-Verlag Lecture Notes in Biomathematics 56 (1984)  
<http://biotech.law.lsu.edu/cphl/Models/gon/index.htm>

### C.5.2 Partner Notification

- C.5.2.1 Partner, or contact, notification is the process of telling persons that they have been exposed to a communicable disease.
- C.5.2.2 This has been opposed on privacy grounds.
  - C.5.2.2.1 It would interfere with the right to avoid knowing that one was exposed to HIV.
  - C.5.2.2.2 If the contact is monogamous, it is impossible to hide the identity of the person who exposed them.

### C.5.3 Benefits and Costs of Contact Tracing and Partner Notification

- C.5.3.1 HIV is hard to catch, so many persons who are exposed can be warned before they are infected.  
Judson, FN, "Partner notification for HIV control." Hosp Pract (Off Ed) 25(12): 63-70, 73. (1990)
- C.5.3.2 Persons who need help in avoiding exposure, such as poor women, can be given social service support.
- C.5.3.3 Contact tracing and partner notification is expensive because HIV is now so

common.

- C.5.3.3.1 The benefit of preventing cases of HIV is very high.
- C.5.3.3.2 The cost can be lowered with an effective national reporting system that eliminates the need to re-investigate previously identified carriers.
- C.5.3.3.3 Most HIV control efforts are funded by the federal government, which has not made contact tracing and partner notification a priority.

#### C.6 Impediments to Routine Testing

- C.6.1 HIV cannot be controlled and persons with HIV cannot get the best medical care until HIV is treated the same as other diseases.
- C.6.2 Consent to HIV testing
  - C.6.2.1 HIV testing should be a routine part of medical care.
  - C.6.2.2 Many states have special laws for consent to HIV testing and require onerous extra paperwork to order HIV tests.
  - C.6.2.3 Most of these requirements arose from fears of HIV information being leaked to employers and others.
  - C.6.2.4 These requirements are unique to HIV.
  - C.6.2.5 There are also special medical record keeping requirements for HIV data in some states.

#### C.6.3 HIPAA

- C.6.3.1 Whatever the original concerns about privacy of HIV information, HIPAA has now imposed a rigorous national medical information privacy standard.
- C.6.3.2 HIPAA standards are adequate to protect HIV information.

#### C.7 Attacks on Other Public Health Laws

- C.7.1 Since AIDS was the best funded public health law issue in the 1980s and 1990s, all public health law was seen as AIDS law.
- C.7.2 AIDS activists and civil libertarians lobbied state legislatures to weaken other public health laws to limit the state's ability to use traditional public health measures in other areas.
- C.7.3 Quarantine and isolation laws were the main target, but other disease control laws also suffered.
- C.7.4 The argument was that the courts, especially the United States Supreme Court, would no longer accept traditional public health laws.
- C.7.5 This has been pushed through model public health law initiatives and by NGOs such as the Turning Point Project.

C.7.6 With the exception of a very small number of aberrant state decisions, the courts have not rejected public health laws.

Edward P. Richards, The Jurisprudence Of Prevention: The Right Of Societal Self-Defense Against Dangerous Persons, 16 Hast Const L Q 320 (1989)  
<http://biotech.law.lsu.edu/cphl/articles/hastings-Contents.htm>

C.7.7 Ironically, if anything, the Supreme Court is more likely to uphold public health laws now than it was 30 years ago.

## D Where Do We Go From Here?

### D.1 Why HIV Control Matters to National Security

D.1.1 The United States must have a working national reporting and communicable disease investigation system if it is to be prepared for emerging infectious diseases and bioterrorism.

D.1.2 This system cannot be a shadow plan, pulled off the shelf when there is an emergency. It must be part of working disease investigation system that used every day or it will be impossible to maintain staffing or readiness. Health departments around the country have been losing critical staff for years and are less able to do large scale disease investigation than they were in years past.

D.1.3 HIV consumes much more money than any other communicable diseases and probably more than any other public health problem, yet little of this money supports disease control.

D.1.4 HIV funding could support the public health infrastructure - both people and information technology - necessary to respond to public health emergencies.

### D.2 What can the Federal Government Do?

D.2.1 Most goals can be reached with funding incentives and do not require national public health laws.

D.2.2 Actions that states should have to take to qualify for federal HIV funding.

D.2.2.1 End anonymous testing.

D.2.2.2 Require named reporting of all positive HIV tests.

D.2.2.3 End all special requirements for HIV testing so that physicians can order HIV tests and handle HIV information the same way as all other medical tests.

D.2.2.4 Require adequate staffing in primary disease control programs

D.2.2.5 Require appropriate expertise, including the board certified public health physicians as program directors

D.2.3 Federal funding priorities

D.2.3.1 Since the federal government shapes disease control through its funding, it must change its priorities to encourage proper disease control for HIV.

D.2.3.2 The federal government should fund:

D.2.3.2.1 Contact tracing

D.2.3.2.2 Partner Notification

D.2.3.2.3 Uniform disease reporting

D.2.3.2.4 A national HIV clearinghouse for disease reports and tracking of infected individuals.

D.2.3.2.5 A national system for assuring that infected persons receive up to date information on HIV treatment and available social services.

D.2.3.2.6 Public health law projects designed to protect and expand traditional disease control powers.

End of Document