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## HEALTH LAW SYMPOSIUM

- WHERE IS THE QUALITY IN THE HEALTH CARE QUALITY IMPROVEMENT ACT OF 1986?

by *THADDEUS J. NODZENSKI*

- 
- THE WOMAN'S RIGHT TO KNOW: A MODEL APPROACH TO THE INFORMED CONSENT OF ABORTION

by *SUSAN OLIVER RENFER, RANDAL SHAHEEN, and MICHAEL HEGARTY*

- 
- MANDATORY DISCLOSURE OF HIV BLOOD TEST RESULTS TO THE INDIVIDUALS TESTED: A MATTER OF PERSONAL CHOICE NEGLECTED

by *MICHAEL L. CLOSEN*

- 
- ARE WE OUTLAWING MOTHERHOOD FOR HIV-INFECTED WOMEN?

by *SCOTT H. ISAACMAN*

- 
- COMBATting AIDS'S ACOUSTIC SHADOW: ILLINOIS ADDRESSES THE PROBLEMS OF CRIMINAL TRANSFER OF HIV

- 
- *WASHINGTON V. HARPER*: THE SUPREME COURT DEFINES PROCEDURAL DUE PROCESS IN THE PRISON
- 



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# Mandatory Disclosure of HIV Blood Test Results to the Individuals Tested: A Matter of Personal Choice Neglected

Michael L. Closen\*

## I. INTRODUCTION

The constitutional rights of privacy and liberty are closely related and seem inseparable at times.<sup>1</sup> In the era of HIV/AIDS disease,<sup>2</sup> the concepts of individual privacy and liberty as they re-

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\* Professor of Law, John Marshall Law School; Adjunct Professor of Law, St. Thomas University; B.S., M.A., Bradley University; J.D., University of Illinois.

A recognized authority on HIV/AIDS, Professor Closen teaches courses on AIDS law at two law schools, was editor and co-author of the first casebook on the subject entitled *AIDS: Cases and Materials* (1989), was co-author of *AIDS Law in a Nutshell* (1990), and was a contributor to the treatise *Legal Aspects of AIDS* (1990).

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1. Courts sometimes rely upon both concepts to decide a single issue. *See, e.g., In re A.C.*, 573 A.2d 1235, 1248 (D.C. 1990) (referring to a woman's "liberty and privacy interests and bodily integrity" on the issue of whether a court should order the caesarean delivery of a terminally ill patient's baby); *see also* Johnson, *The Creation of Fetal Rights: Conflicts with Women's Constitutional Rights to Liberty, Privacy and Equal Protection*, 95 YALE L.J. 599 (1986). The constitutional analysis in the right-to-die cases had rested principally upon the right to privacy, until recently when the Supreme Court proclaimed that a liberty analysis was more appropriate. "Although many state courts have held that a right to refuse treatment is encompassed by a generalized constitutional right of privacy, we have never so held. We believe this issue is more properly analyzed in terms of a Fourteenth Amendment liberty interest." *Cruzan v. Director, Mo. Dep't of Health*, 110 S. Ct. 2841, 2851 n.7 (1990) (citing *Bowers v. Hardwick*, 478 U.S. 186, 194-95 (1986)).

2. The abbreviation HIV/AIDS stands for Human Immunodeficiency Virus/Acquired Immune Deficiency Syndrome. This designation is preferred over reference to AIDS alone because the focus upon AIDS is not representative of the full course of the disease, which starts with HIV infection and the gradual erosion and suppression of the immune system. After becoming infected with HIV, people may remain in an asymptomatic state for up to nine years or longer. Once people with HIV develop symptoms and are diagnosed as having AIDS Related Complex (ARC) (a label that seems to be falling out of favor) or AIDS, those persons may live with the disease for several years (possibly as long as eight to ten years). Hence, HIV/AIDS can appropriately be considered a chronic disease condition. *See* REPORT OF THE PRESIDENTIAL COMMISSION ON THE HUMAN IMMUNODEFICIENCY VIRUS EPIDEMIC 8, 15 (1988) [hereinafter PRESIDENTIAL COMMISSION REPORT], U.S. DEP'T OF HEALTH AND HUMAN SERVS., SURGEON GENERAL'S REPORT ON ACQUIRED IMMUNE DEFICIENCY SYNDROME 11-12, 20 (1986) [hereinafter SURGEON GENERAL'S REPORT]; R. JARVIS, M. CLOSEN, D. HERMANN &

late to HIV blood test<sup>3</sup> results have two distinct applications. First, an individual may have a privacy or liberty concern about the disclosure to others of medical information identifying the individual's HIV/AIDS condition. This subject seems to come to mind first for almost everyone confronted with an inquiry about confidentiality, disclosure, or self-determination. Confidentiality of the HIV test results has been extensively treated in the statutes and the literature.<sup>4</sup> Additionally, courts have begun to confront allegations of unlawful dissemination of the highly sensitive and personal information about a plaintiff's HIV/AIDS status.<sup>5</sup> That particular privacy concern is not the subject of this Article.

Instead, this Article focuses upon an almost completely overlooked concern of many individuals under present HIV testing statutes—the right not to be informed of their HIV status. Most of these statutes require that the individual tested be informed of the

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A. LEONARD, AIDS LAW IN A NUTSHELL 22-23 (1990) [hereinafter R. JARVIS & M. CLOSEN, AIDS NUTSHELL].

The term "AIDS" is obsolete. "HIV infection" more correctly defines the problem. The medical, public health, political, and community leadership must focus on the full course of HIV infection rather than concentrating on later stages of the disease (ARC and AIDS). Continual focus on AIDS rather than the entire spectrum of HIV disease has left our nation unable to deal adequately with the epidemic.

*Id.* PRESIDENTIAL COMMISSION REPORT at xvii.

3. A serologic test for antibodies to HIV (formerly HTLV-III or LAV) was developed, licensed, and placed into widespread use in this country in the spring of 1985. Importantly, it does not test directly for the virus, but only for antibodies that are produced in reaction to infection with the virus. The full HIV test protocol should consist of two important steps. First, an enzyme-linked immunosorbent assay (ELISA) test is administered as a preliminary screening device to identify those blood samples that may be HIV-infected. Any blood specimen that tests repeatedly seropositive for HIV on ELISA testing should then be submitted to a second level of testing, the Western blot test. The Western blot serves as a confirmatory test to ascertain the presence of HIV antibodies or to disprove the existence of HIV antibodies in particular blood samples that have shown positive at the ELISA testing level. See PRESIDENTIAL COMMISSION REPORT, *supra* note 2, at 198, 201; M. CLOSEN, D. HERMANN, P. HORNE, S. ISAACMAN, R. JARVIS, A. LEONARD, R. RIVERA, M. SCHERZER, G. SCHULTZ & M. WOJCIK, AIDS: CASES AND MATERIALS 148-49 (1989) [hereinafter M. CLOSEN, AIDS CASES]; R. JARVIS & M. CLOSEN, AIDS NUTSHELL, *supra* note 2, at 17-18.

4. See generally Closen, Connor, Kaufman & Wojcik, AIDS: Testing Democracy—*Irrational Responses to the Public Health Crisis and the Need for Privacy in Serologic Testing*, 19 J. MARSHALL L. REV. 835 (1986) [hereinafter Closen, *Testing Democracy*]; Closen & Isaacman, *The Duty to Notify Private Third Parties of the Risks of HIV Infection*, 21 J. HEALTH & HOSP. L. 295 (1988) [hereinafter Closen, *Duty to Notify*]; Closen & Power, *AIDS In the Workplace*, COMPLETE LAWYER, Summer 1988, at 14 [hereinafter Closen, *Workplace AIDS*]; Comment, *HIV/AIDS Confidentiality: Are Computerized Medical Records Making Confidentiality Impossible?*, 4 SOFTWARE L.J. 93 (1990).

5. See, e.g., *Harris v. Thigpen*, 727 F. Supp. 1564 (M.D. Ala. 1990); *McCune v. Neitzel*, 235 Neb. 754, 457 N.W. 2d 803 (1990).

test result, especially if the result is positive (indicating infection with HIV).<sup>6</sup> The tested individual is afforded no choice in the matter. Thus, for example, when applicants for life or health insurance,<sup>7</sup> blood, semen, or organ donors,<sup>8</sup> prisoners,<sup>9</sup> or medical and mental patients<sup>10</sup> are tested for HIV, statutes provide that those individuals must be told of their results. Moreover, many of these statutes require that the individual be counseled, particularly if the individual tests seropositive.<sup>11</sup>

This author strenuously disapproves not only of almost all HIV testing conducted without the informed consent of the individual

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6. See statutes cited *infra* notes 34-42 and accompanying text.

7. See, e.g., FLA. STAT. ANN. § 627.429(4)(c) (West Supp. 1990); N.Y. PUB. HEALTH LAW §§ 2781(5), 2782(1)(a),(j) (Consol. 1990); N.C. GEN. STAT. § 130A-148(g) (1989); see also sample standard consent form for life and health insurance (on file with author).

8. See, e.g., ARIZ. REV. STAT. ANN. § 32-1483 (1989) (blood donors are to be notified of positive HIV test results); CAL. HEALTH & SAFETY CODE § 1603.3(a) (West 1990); LA. REV. STAT. ANN. §§ 1062.1(c), 1299.142(B)(1) (West 1990); MD. HEALTH-GEN. CODE ANN. § 18-334(b),(c) (1990) (requires notification to a donor when there is a positive test result); N.Y. PUB. HEALTH LAW §§ 2781(6), 2782(1)(a) (Consol. 1990); WIS. STAT. ANN. § 146.023(1) (West 1990); see also N.C. GEN. STAT. § 130A-148(g) (1989); N.D. CENT. CODE § 23-07.5-05(1)(d),(e) (Supp. 1989).

9. See, e.g., MD. HEALTH-GEN. CODE ANN. § 18-338(b),(d),(f) (1990) (allows testing without consent of prisoner if there is a possible exposure of a correctional employee to HIV; and requires counseling if test result is positive); MO. ANN. STAT. §§ 191.653(3), .656(2)(1)(e), .659 (Vernon Supp. 1991); N.Y. PUB. HEALTH LAW §§ 2781(5), 2782(1)(l)-(o) (Consol. 1990); N.C. GEN. STAT. § 130A-148(g) (1989); see also S.C. CODE ANN. §§ 44-29-100, -110 (Law. Co-op. 1989) (allows testing of prisoners for HIV and denies discharge of those who test positive until release is recommended by health department).

10. See, e.g., MO. ANN. STAT. §§ 191.653(3), .656(2)(1)(e), .662 (Vernon Supp. 1991) (testing and disclosure to individuals in drug treatment programs and mental health patients); N.H. REV. STAT. ANN. § 141-F:7(II) (1988) (testing of and disclosure to medical patients); WIS. STAT. ANN. § 146.025(3) (West Supp. 1990) (testing of and disclosure to mental patients who pose risk of transmission of HIV to other patients); see also, CAL. HEALTH & SAFETY CODE § 199.25b (West 1990); N.C. GEN. STAT. § 130A-148(g) (1989); S.C. CODE ANN. § 44-29-230 (Law. Co-op. 1989) (if possible accidental HIV transmission from patient to health care worker, patient can be tested with consent and must be told of result).

11. See, e.g., FLA. STAT. ANN. § 627.429(4)(c) (West Supp. 1990); ILL. REV. STAT. ch. 111 1/2, para. 7307(b),(c) (1989) (appropriate counseling to be provided when an individual tests positive and when informed consent to test was not required due to a statutory exception); MD. HEALTH-GEN. CODE ANN. § 18-334(c)(2) (1990) (providing that a semen, blood, or tissue donor who tests positive be informed of the availability of counseling); N.M. STAT. ANN. § 24-2B-4 (Supp. 1990); TEX. REV. CIV. STAT. ANN. art. 4419b-4, § 1.028 (Vernon 1990) (posttest counseling provided following a positive HIV test); see also N.H. REV. STAT. ANN. § 141-F:7(III) (1988) (providing for notification and counseling of parent or legal guardian of minor or mentally incompetent person who tests seropositive); WASH. REV. CODE ANN. § 70.24.330 (1988) (requiring counseling for insurance applicants who test positive).

tested,<sup>12</sup> but also of statutes which require that people be told the results of their HIV tests. Each individual should have the right to decide in advance whether he or she will be told of the HIV test result. The constitutional rights of liberty and privacy mandate that citizens be permitted to decline forced disclosure of this information. Moreover, allowing people to choose is better public policy than forcing their HIV test results upon them.

This Article begins with a review of various state legislative provisions on test result disclosure. The Article then explores the absence of medical or legal justifications for compelled disclosure of HIV results to the persons tested and the reasons why an individual rightly might not want to know his or her HIV status. It then briefly discusses statutorily mandated counseling for those who test positive. The Article concludes with a short commentary on the tort and criminal law implications of mandatory disclosure to and counseling of those who test seropositive for HIV.

## II. STATUTES ON MANDATORY HIV TEST RESULT DISCLOSURE

As might be anticipated, the statutes on HIV test result disclosure vary markedly from state to state. However, among the numerous variations in specific language and terms, four basic categories can be discerned. First, many states require that individuals who are tested for HIV must be informed of their test results.<sup>13</sup> Other states give state officials or agents the discretion to advise individuals of their HIV results.<sup>14</sup> Some states do not address the subject at all.<sup>15</sup> Finally, a few states permit some tested individuals to elect whether they receive their HIV test results.<sup>16</sup>

Several points common to many of the HIV testing statutes and applicable to all four categories discussed below should be noted. First, the statutes sometimes do not require that HIV testing include a confirmatory procedure.<sup>17</sup> In other words, statutes often

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12. See Closen, *Testing Democracy*, *supra* note 4; Closen, *Duty to Notify*, *supra* note 4; Closen, *Workplace AIDS*, *supra* note 4. But see Closen, *A Call For Mandatory HIV Testing and Restriction of Certain Health Care Professionals*, 9 ST. LOUIS U. PUB. L. REV. 421 (1990) [hereinafter Closen, *Call for HIV Testing*]. The author's position is not altered by the inclusion of mandatory counseling provisions in the mandatory disclosure statutes.

13. See statutes cited *infra* notes 34-39 and accompanying text.

14. See statutes cited *infra* notes 40-42 and accompanying text.

15. See statutes cited *infra* note 43 and accompanying text.

16. See statutes cited *infra* note 44 and accompanying text.

17. For example, many statutes make no reference to the need to confirm a positive HIV test. See, e.g., MD. HEALTH-GEN. CODE ANN. §§ 18-333-339 (1990); N.J. STAT.

establish no protocol to insure the accuracy of HIV testing, such as a procedure demanding that any repeatedly reactive results on an ELISA test<sup>18</sup> be confirmed by the more accurate Western blot test.<sup>19</sup> The ELISA test is intended merely as a less expensive and overly sensitive initial screening test when massive numbers of blood samples are to be processed. The Western blot is a more expensive and less sensitive test thought to be more than 99 percent accurate when used as part of a full testing protocol.<sup>20</sup> Thus, many more samples will test seropositive for HIV if submitted only to ELISA testing, than if also submitted to the Western blot analysis. Therefore, if people were informed of test results based solely upon ELISA processing, many of them would be erroneously advised that they are infected with HIV.<sup>21</sup>

Second, although many HIV testing statutes generally require informed consent before testing, such provisions do not serve to

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ANN. §§ 26:5C-5 to -14 (West Supp. 1990); N.Y. PUB. HEALTH LAW § 2780 (Consol. 1990); N.D. CENT. CODE §§ 23-07.4-01 to -07.5-08 (Supp. 1989); R.I. GEN. LAWS § 23-6-10 (1989); S.C. CODE ANN. § 44-29-20 (Law. Co-op. 1989). Illinois does not expressly provide for confirmation of statutory HIV testing, but does have an odd requirement that the test subject be informed about the availability of confirmatory testing. ILL. REV. STAT. ch. 111 1/2, para. 7305 (1989); see also TEX. REV. CIV. STAT. ANN. art. 4419b-4, § 1.02(7) (Vernon 1990) (refers to informing the test subject of "the potential need for confirmatory testing," without further explanation). Several statutes do include a general reference to some sort of confirmatory testing without any description of specific protocol. See, e.g., GA. CODE ANN. § 31-22-9.1(a)(5) (Supp. 1990) (a "confirmed positive HIV test" requires at least two separate types of HIV tests to be administered); IOWA CODE ANN. § 141.22(6) (West 1990) (referring to "confirmation according to prevailing medical technology of a positive HIV-related test"); KAN. STAT. ANN. § 65-6001(c) (Supp. 1989) (referring to a confirmatory AIDS test); KY. REV. STAT. ANN. §§ 214.454(1), 214.458(7), and 214.464(2) (Michie/Bobbs-Merrill Supp. 1988) (referring to confirmatory positive test for HIV); MO. ANN. STAT. § 191.653(3) (Vernon Supp. 1991) (referring to "confirmed" test result, with no further explanation of protocol); N.C. GEN. STAT. § 130A-148(a) (1989) (referring to confirmatory testing); OHIO REV. CODE ANN. § 3701.24.1(B)(1) (Anderson Supp. 1989) (requires state director of health to define the phrase "confirmed positive test result"); WIS. STAT. ANN. § 146.025(1)(g) (West Supp. 1990) (defining a "validated test result" as an HIV test that meets the validation requirements deemed necessary by the state epidemiologist). For statutes that set out a testing protocol, see LA. REV. STAT. ANN. § 1299.141(1), (5) (West 1990) (referring to the Western blot); MONT. CODE ANN. § 50-16-1003(6) (1989) (referring to both an ELISA and a Western blot test).

18. See *supra* note 3 and accompanying text; see also Closen, *Testing Democracy*, *supra* note 4, at 872-73.

19. See *supra* note 3 and accompanying text; see also Closen, *Testing Democracy*, *supra* note 4, at 873.

20. See *supra* note 3 and accompanying text; see also Closen, *Testing Democracy*, *supra* note 4, at 873.

21. See R. JARVIS & M. CLOSEN, AIDS NUTSHELL, *supra* note 2, at 17-18; see also Benenson, Peddecord, Hofherr, Ascher, Taylor & Hearn, *Reporting the Results of Human Immunodeficiency Virus Testing*, 262 J. A.M.A. 3435 (1990) (details erroneous and confusing laboratory reporting of HIV results).

dispel the objections raised in this Article about mandatory HIV result disclosure to the individuals tested. Although refusal to consent certainly prevents the administration of an HIV test and the generation of an HIV test result, so many statutes include so many exceptions that the exceptions appear to be swallowing up the field. Hence, there are exceptions that allow testing without consent of prison inmates,<sup>22</sup> medical and mental patients,<sup>23</sup> defendants arrested for certain criminal offenses,<sup>24</sup> donors of organs, blood, semen, and other human tissue,<sup>25</sup> and so on.

Furthermore, many situations are not conducive to true consent. Military personnel and recruits,<sup>26</sup> applicants for life and health insurance,<sup>27</sup> immigrants,<sup>28</sup> Job Corps applicants,<sup>29</sup> and certain for-

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22. See, e.g., *Dunn v. White*, 880 F.2d 1188 (10th Cir. 1989), *cert. denied*, 110 S. Ct. 871 (1990) (upholding mandatory HIV testing of prison inmate); *Harris v. Thigpen*, 727 F. Supp. 1564 (M.D. Ala. 1990) (upholding HIV testing of prison inmates); MD. HEALTH-GEN. CODE ANN. § 18-338(b) (1990) (no informed consent required if possible exposure of a correctional employee to HIV has occurred); MO. ANN. STAT. § 191.659 (Vernon Supp. 1991); OHIO REV. CODE ANN. § 3701.24.2(E)(4) (Anderson Supp. 1989).

23. Medical patients can be tested without their informed consent. See, e.g., ILL. REV. STAT. ch 111 1/2, para. 7308(b) (1989) (when physician determines that it is medically indicated that patient should be tested); OHIO REV. CODE ANN. § 3701.24.2(E)(1),(5),(6) (Anderson Supp. 1989) (in medical emergency, when necessary for diagnosis and treatment, or in the case of possible accidental exposure to HIV); OR. REV. STAT. § 433.080 (Supp. 1990) (upon court order without consent of test subject if there may have been an accidental exposure to HIV); R.I. GEN. LAWS § 23-6-14(a),(e) (1989) (allowing health care providers to test infants under one year of age and to test patients if there has been a possible accidental transmission of HIV to a health care provider). Certainly, numerous statutes permit disclosure of positive HIV results to the treating physician(s) of the test subject. See, e.g., KY. REV. STAT. ANN. § 214.420(3)(a) (Michie/Bobbs-Merrill Supp. 1988). Some statutes permit the testing of mental patients. See, e.g., WIS. STAT. ANN. § 146.025(2)(b) (West Supp. 1990) (if mental patient "poses a significant risk of transmitting HIV to another resident or patient"); see also IOWA CODE ANN. § 141.63(d)(2) (West Supp. 1990) (requiring disclosure to person who tests positive for HIV if physician determines that there is imminent danger of transmission to a third party); KY. REV. STAT. ANN. § 214.464(2) (Michie/Bobbs-Merrill 1990) (requiring disclosure to emergency blood transfusion recipient of the results of a positive HIV test on the blood received by the donee).

24. See, e.g., *Haywood County v. Hudson*, 740 S.W.2d 718 (Tenn. 1987) (upholding forced HIV testing of felony arrestee who told police he suffered from AIDS); ARK. STAT. ANN. § 16-82-101(b)(1) (Supp. 1989) (allowing HIV testing of arrestees charged with criminal sexual offenses); see also GA. CODE ANN. § 31-17A-2 (Supp. 1990) (permitting court-ordered testing without consent when test subject presents health threat to others); MO. ANN. STAT. § 191.674(1) (Vernon Supp. 1991) (same); W. VA. CODE § 16-3C-2(f)(2),(4) (1991) (mandatory testing for persons convicted of certain sexual offenses and for persons who may be a danger to the public health).

25. See, e.g., N.H. REV. STAT. ANN. § 141-F:5(I) (Supp. 1989).

26. See Wilers, *Putting AIDS to the Test: Tough Questions About the Merits of Mass Screening*, TIME, Mar. 2, 1987, at 60 (noting that by the end of 1987, the military would have screened three million members of the armed forces).

27. See MO. ANN. STAT. § 191.671 (Vernon Supp. 1991) (allowing life and health

eign service employees<sup>30</sup> might refuse HIV testing, but such refusals may have serious adverse consequences including loss, denial, or restriction of employment, denial of entry into the country, or denial of life and health insurance. Moreover, some health care professionals may soon face reprisals for failure to submit to HIV testing.<sup>31</sup> In any event, the informed consent opportunity does not ordinarily extend to the later decision to decline to learn of one's HIV test result. As noted above, some HIV testing statutes do not even mandate informed consent for the testing itself.

As a practical matter, some subjects of HIV testing may successfully dodge the efforts of government agents to communicate the results of their HIV tests. An HIV test result, under present technology, is not available until a few days after the blood sample is obtained.<sup>32</sup> Hence, unless the test subject is confined involuntarily in a hospital, jail, or other facility, the subject may simply walk away and not return to receive the mandatory HIV disclosure.<sup>33</sup> However, we should not encourage that kind of situation. People

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insurance companies to test for HIV upon informed consent of applicant); OR. REV. STAT. § 433.045(7) (Supp. 1990) (same); R.I. GEN. LAWS § 23-6-24(a),(b) (1989) (allowing life and health insurance companies to test for HIV upon informed consent of applicant); Schatz, *The AIDS Insurance Crisis—Underwriting or Overreaching*, 100 HARV. L. REV. 1782 (1987); see also statutes cited *supra* note 7 and accompanying text.

28. See 42 C.F.R. § 34.4(a)(1)(i) (1990) (serologic testing for HIV required of all applicants for immigrant visas); S. SONTAG, AIDS AND ITS METAPHORS 33 (1989) (noting that "testing positive now makes one ineligible to immigrate everywhere").

29. See Wilers, *supra* note 26, at 60 (noting plans to test some 60,000 Job Corps applicants).

30. See, e.g., Local 1812, Am. Fed'n of Gov't Employees v. United States, 662 F. Supp. 50 (D.D.C. 1987).

31. See *Leckelt v. Board of Comm'rs of Hosp. Dist. No. 1*, 909 F.2d 820 (5th Cir. 1990) (nurse who refuses to submit to HIV test may be discharged by employer); Closen, *Call for HIV Testing*, *supra* note 12; *Woman with AIDS Tied to Her Dentist Will Get \$1 Million*, N.Y. Times, Jan. 24, 1991, at A13, col. 1 [hereinafter *Woman With AIDS*] (reporting that the insurance carrier for a Florida dentist with AIDS settled a claim by a former patient who asserted that she contracted HIV from the dentist, after the Centers for Disease Control confirmed the probability of the transmission in this case); see also R.I. GEN. LAWS § 23-6-14(d)(ii) (1989) (requiring that a person, such as a health care professional, who may have been occupationally exposed to an accidental transmission of HIV must submit to an HIV test and must test negative in order to obtain an HIV test of another without that person's informed consent). *But see*, *Glover v. Eastern Neb. Community Office of Retardation*, 867 F.2d 461 (8th Cir.), *cert. denied*, 110 S. Ct. 321 (1989) (risk of HIV transmission to mentally retarded patients too minimal to justify mandatory HIV testing of agency employees).

32. Blood samples must be sent to outside laboratories for testing and analysis, and the results must then be returned. R. JARVIS & M. CLOSEN, AIDS NUTSHELL, *supra* note 2, at 17.

33. See FLA. STAT. ANN. § 381.609(3)(c) (West Supp. 1990) ("the person ordering the test shall schedule a return visit with the test subject for the purpose of disclosing the test results and conducting post test counseling").



should not have to hide from government agents or avoid answering their telephones or collecting their mail for fear of receiving the HIV test results.

The first category of mandatory HIV testing statutes consists of the large group of laws that require individuals to be told of their HIV test results.<sup>34</sup> For example, in New Hampshire, a public health provision on HIV testing provides that "[t]est results shall be disclosed by the physician or the person authorized by the physician to the person who was tested."<sup>35</sup> Similarly, Minnesota's law on testing for HIV in the context of possible exposure of emergency medical services personnel to the virus reads: "The facility that receives the patient shall inform the patient . . . of test results for all tests conducted under this chapter."<sup>36</sup> Other laws, such as North Carolina's, provide very simply that "[p]ersons tested for AIDS virus infection shall be notified of test results."<sup>37</sup> Occasionally, these statutes provide for disclosure to the test subject only if the result is positive.<sup>38</sup> For example, the Florida insurance code states that "[a]n applicant shall be notified of a positive test result by a physician designated by the applicant."<sup>39</sup>

The second category of laws authorizes government officials and their agents to tell a person of his or her HIV status, but do not expressly state that the individual must be told of the test result.<sup>40</sup> The West Virginia statute is typical. It states that "[n]o person may disclose . . . the results of [an HIV-related test] . . . except to

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34. LA. REV. STAT. ANN. §§ 40:1062.1(C), 40:1299.142(B)(1) (West 1990); MONT. CODE ANN. § 50-16-1007(1),(4) (1989) (requiring informed consent for testing and requiring that the test subject be told of the results); WIS. STAT. ANN. § 146.025(2)(b)3b (West Supp. 1990); see also MO. ANN. STAT. §§ 191.653(3), 191.656(2)(1)(e) (Vernon Supp. 1991) (apparently mandating test result disclosure to the test subject).

35. N.H. REV. STAT. ANN. § 141-F:7(II) (Supp. 1989).

36. MINN. STAT. ANN. § 144.767(2) (West Supp. 1991).

37. N.C. GEN. STAT. § 130A-148(g) (1989).

38. See, e.g., ARIZ. REV. STAT. ANN. § 32-1483 (1989); see also IOWA CODE ANN. § 141.6(3)(d)(2) (West Supp. 1990) (requiring disclosure of a positive HIV test to the person tested if a physician determines that there is imminent danger of HIV transmission to a third party); KY. REV. STAT. ANN. § 214.464(2) (Michie/Bobbs-Merrill 1990) (requiring disclosure to emergency blood transfusion recipient of positive HIV test on blood received by the donee.)

39. FLA. STAT. ANN. § 627.429(4)(c) (West Supp. 1990).

40. See, e.g., CAL. HEALTH & SAFETY CODE § 199.24(a) (West 1990); ILL. REV. STAT. ch. 111 1/2, para. 7309(a) (1989); N.Y. PUB. HEALTH LAW §§ 2781(5), 2782(1) (Consol. 1990) (fairly presumed that the test subject will be informed of results); N.D. CENT. CODE § 23-07.5-05 (Supp. 1989); OHIO REV. CODE ANN. § 3701.24.3(B)(1)(a) (Anderson Supp. 1989) (authorizing disclosure to legal guardian, spouse, or any sexual partner); VA. CODE ANN. § 32.1-36.1 (A)(1) (1991); W. VA. CODE § 16-3C-3(a)(1) (Supp. 1990); WASH. REV. CODE § 70.24.105(2)(a) (1988).

the following persons: (1) the subject of the test."<sup>41</sup> These statutes give unlimited authority to government agents to tell a person of his or her HIV result; they ordinarily impose no restrictions on that broad discretion. Only occasionally do these laws include any prerequisites for disclosure to the subject of the test. For instance, the Texas statute provides that "[a] test result indicating the presence of HIV infection may not be revealed to the person tested without giving that person the immediate opportunity for individual, face-to-face posttest counseling."<sup>42</sup> As discussed below, one suspects that individuals tested are routinely being told of their test results under this type of provision.

A third category of state enactments makes no reference to who is required, or even entitled, to be informed of the HIV test results.<sup>43</sup> In all likelihood, people who are tested for HIV in these states routinely are told of the test results because the statutes do not prohibit disclosure. Moreover, those administering or supervising HIV tests might automatically assume that a tested person should be or must be informed of the test result (in part because the subjects of other kinds of tests are almost always told of the results). Test result disclosure is a matter of habit or standard operating procedure in the health care field.

A fourth category of statutes actually allows the individual tested the choice of whether he or she will receive the HIV results, but this kind of provision is highly unusual. The Delaware law provides a good illustration of this approach. It provides that "[a]ny person on whom an HIV-related test was performed without first having obtained informed consent . . . shall be given notice

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41. W. VA. CODE § 16-3C-3(a)(1) (1991).

42. TEX. REV. CIV. STAT. ANN. art. 4419b-4, § 4.01(a) (Vernon Supp. 1991).

43. For example, in Georgia, the statutory scheme implies that the test subject will be notified, although no specific provision requires such notification. See GA. CODE ANN. § 31-22-9.2 (c),(d) (Supp. 1990) (informed consent test subject's medical or emotional state would make disclosure of test result injurious to the subject's health; appropriate counseling required "with regard to the test results"); see also, e.g., ARK. STAT. ANN. §§ 16-82-101, 20-15-901 to -904 (Supp. 1989) (allowing victim of certain sex offenses to learn result of HIV test of alleged offender, but not otherwise addressing who might get access to test results); KAN. STAT. ANN. § 65-6002 (Supp. 1989) (allowing disclosure in medical emergency only to medical personnel, and allowing Secretary of Health and Environment to provide by regulation for disclosure to others); KY. REV. STAT. ANN. § 214.420(3)(a) (Michie/Bobbs-Merrill Supp. 1988) (permits disclosure to the treating physician, but does not mention disclosure to the person tested or anyone else in the absence of informed consent); N.J. STAT. ANN. § 26:5c-8(b)(3) (West Supp. 1990) (permits disclosure to treating medical personnel, but does not mention disclosure to anyone else without informed consent); R.I. GEN. LAWS § 23-6-17 (Supp. 1990) (allowing result disclosure to a physician and very limited others, but making no reference to disclosure to the test subject).

promptly, personally and confidentially that a test sample was taken and the results of such test may be obtained upon request."<sup>44</sup>

### III. MEDICAL AND LEGAL OBJECTIONS TO COMPULSORY DISCLOSURE TO THE INDIVIDUALS TESTED

#### A. *Compulsory Disclosure Affects Fundamental Rights*

Because compulsory disclosure infringes upon every person's fundamental right to personal choice, the basic right to self-determination, we should oppose mandatory disclosure of HIV results to tested individuals. Our society and our law cherish this right as significant unto itself, regardless of the underlying subject matter involved. In the context of the abortion controversy, for instance, the overriding concern for many is a woman's right to personal choice or to preserve her autonomy in deciding whether to undergo an abortion.<sup>45</sup> Similarly, the right-to-die debate focuses mainly upon the right of those persons in dire health conditions to elect to refuse or withdraw extraordinary life support efforts.<sup>46</sup> This right derives from the right to self-determination. Finally, consider the issue of terminally ill pregnant women who refuse to undergo cesarean deliveries of their babies. Again, the woman's right of personal decision making has been the central concern.<sup>47</sup> Simply put, this societal and legal approach is correct, for when there is no compelling public or governmental interest, the fundamental rights of each citizen must remain paramount.

Why should we treat HIV reporting any differently than we treat nearly every other aspect of health and medicine? In other settings, we do not deprive individuals of their freedom of personal choice. We do not, for example, require women to undergo and obtain the results of mammograms; we do not mandate that adults learn their blood pressure statistics; and we do not dictate that adults submit to chest x-rays and receive their x-ray results. Yet each of these tests is associated with detection of potentially life-threatening ailments.<sup>48</sup> We do not even prohibit individuals from putting their lives directly in jeopardy by smoking cigarettes, be-

44. DEL. CODE ANN. tit. 16, § 1202(d) (Supp. 1990).

45. See generally *Webster v. Reproductive Health Servs.*, 492 U.S. 490 (1989); *Thornburgh v. American College of Obstetricians & Gynecologists*, 476 U.S. 747 (1986); *Planned Parenthood Ass'n v. Ashcroft*, 462 U.S. 476 (1983); *City of Akron v. Akron Center for Reproductive Health, Inc.*, 462 U.S. 416 (1983); *Roe v. Wade*, 410 U.S. 113 (1973).

46. See, e.g., *Cruzan v. Director, Mo. Dep't of Health*, 110 S. Ct. 2841 (1990).

47. See, e.g., *In re A.C.*, 573 A.2d 1235 (D.C. 1990); see also, *Johnson*, *supra* note 1.

48. See FUNK & WAGNALLS FAMILY MEDICAL GUIDE 329-32, 556-57, 561-62

coming obese, or engaging in sports such as boxing, auto racing, and sky diving.<sup>49</sup> In addition, with little exception, we certainly do not deprive people of the personal choice of declining to obtain health care or medical treatment.<sup>50</sup> We do not generally require individuals to submit to testing for syphilis, serum hepatitis, or Tay-Sachs (and, in turn, to learn the results of such testing) although those serious disease conditions can be transmitted to others through sexual, casual, and perinatal contact, respectively.<sup>51</sup> If all of this is so, why should the right to self-determination in regard to HIV test result disclosure be treated any differently? In short, it should not be.

Whether the freedom to decline to be informed of one's HIV result is regarded as a right based on privacy or liberty, it should certainly be characterized as fundamental. After all, the issues of death and dying are directly implicated.<sup>52</sup> HIV infection is the precursor of AIDS for virtually all, if not all, individuals who contract the virus,<sup>53</sup> and AIDS is incurable and fatal.<sup>54</sup> A not uncommon metaphor is that the news of one's HIV infection "amounts to a death sentence."<sup>55</sup>

Issues encountered in right-to-die cases seem closely analogous

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(1976) [hereinafter FAMILY MEDICAL GUIDE] (describing high blood pressure test, lung cancer test and breast cancer test).

49. See, e.g., *Health Benefits of Smoking Cessation*, 39 MORBIDITY & MORTALITY WEEKLY REP. 653 (1990) (citing adverse effects of tobacco use and encouraging the reduction and prevention of those effects).

50. See generally *Cruzan v. Director, Mo. Dep't of Health*, 110 S. Ct. 2841 (1990); Lipton, *Do-Not-Resuscitate Decisions in a Community Hospital: Incidence, Implications and Outcomes*, 256 J. A.M.A. 1164 (1986); Annotation, *Patient's Right to Refuse Treatment Allegedly Necessary to Sustain Life*, 93 A.L.R.3d 67 (1979).

51. See M. CLOSEN, AIDS CASES, *supra* note 3, at 26-37; see also FAMILY MEDICAL GUIDE, *supra* note 48, at 377-78, 396-99, 542, 624 (describing tests for serum hepatitis, syphilis and Tay-Sachs).

52. As Justice Brennan observed, "[d]ying is personal. And it is profound. For many, the thought of an ignoble end, steeped in decay, is abhorrent. A quiet, proud death, bodily integrity intact; is a matter of extreme consequence." *Cruzan v. Missouri Dep't of Health*, 110 S. Ct. 2841, 2868 (1990) (Brennan, J., dissenting); see also M. CLOSEN, AIDS CASES, *supra* note 3, at 467-531; R. JARVIS & M. CLOSEN, AIDS NUTSHELL, *supra* note 2, at 1-3.

53. R. JARVIS & M. CLOSEN, AIDS NUTSHELL, *supra* note 2, at 6-7, 14-17 (explaining that HIV invades red blood cells and depresses a person's immune system, rendering that person vulnerable to infections which a healthy immune system would normally fight off); see also *Harris v. Thigpen*, 727 F. Supp. 1564, 1567 (M.D. Ala. 1990) (same); cf. ARK. CODE ANN. §§ 20-15-901 to -904 (Supp. 1989) (emergency clause in original act noted that AIDS ultimately causes premature death of all those infected with HIV).

54. See *Harris*, 727 F. Supp. at 1567 (characterizing AIDS as an "incurable and fatal disease"); Clozen, *Testing Democracy*, *supra* note 4, at 845.

55. See, e.g., *Harris*, 727 F. Supp. at 1572 (referring to the spread of HIV in prison as a harsh punishment "that amounts to a death sentence"); *Doe v. Roe*, 139 Misc. 2d 209,

to those in the HIV/AIDS testing context. In right-to-die cases, courts must decide whether an individual possesses a right to refuse heroic or extraordinary life-support measures when the person has fallen into an irreversible and terminal condition progressing towards death or has fallen into a persistent vegetative state (an irreversible comatose condition).<sup>56</sup> In other words, do individuals have a right to decide to allow themselves to die naturally, rather than be forced by the state to suffer "life" that really amounts to a protracted, painful, demeaning, and agonizing death?

The news of HIV infection presents a similar issue. Does an individual have a right to refuse to be informed of his or her positive HIV test result, which would indicate that the person is in an incurable and terminal condition? In other words, does the state have the right to force people to "live" with the emotionally unsettling and disturbing information that they are really moving down the path of HIV disease toward a protracted, painful, demeaning, and perhaps horrifyingly disfiguring death?<sup>57</sup> Many rational people would prefer not to know, to live apparently healthy and emotionally happy existences until perhaps years later when they are overcome by symptoms that signal undeniably the presence of AIDS. Medical evidence shows that following HIV infection, development of symptoms of illness usually take years, possibly as

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213, 526 N.Y.S.2d 718, 722 (Sup. Ct. 1988) (comparing notice of one's HIV infection "to receiving a death sentence").

56. See, e.g., *Cruzan v. Director, Mo. Dep't of Health*, 110 S. Ct. 2841 (1990).

57. Since the first recognition of AIDS—and even before we had a name for the syndrome—one of the two most common opportunistic diseases to afflict people with HIV/AIDS has been Kaposi's sarcoma, a fairly rare form of cancer. See *Kaposi's Sarcoma and Pneumocystis Pneumonia Among Homosexual Men—New York City and California*, 30 MORBIDITY & MORTALITY WEEKLY REP. 305 (1981). This cancer can become severely disfiguring as it produces blue-black splotches or lesions on the skin (particularly about extremities such as the nose, lips, fingers, and toes, but all over the body as well). Furthermore, those with Kaposi's usually waste away from weight loss (in Africa AIDS is often referred to as "slim" disease), and those sufferers can eventually be reduced to living skeletons. For graphic photographic illustrations, see A. FRIEDMAN-KIEN, *COLOR ATLAS OF AIDS* (1989); Schneiderman & Garibaldi, *Physical Examination of HIV-Infected Patients*, 30 CONSULTANT 33 (1990). Medical science has succeeded, thus far, only in treating symptoms of HIV/AIDS and in prolonging the physiological existences of people with HIV/AIDS, with the result that they are now "falling prey to an array of other maladies." Cowley & Hager, *AIDS: The Next Ten Years*, NEWSWEEK, June 25, 1990, at 20, 22; see also R. JARVIS & M. CLOSEN, *AIDS NUTSHELL*, *supra* note 2, at 19, 22-23. Besides pneumocystis carinii pneumonia and Kaposi's sarcoma, people with HIV/AIDS also may suffer from profound fatigue, profuse night sweating, oral thrush, persistent fevers, swollen lymph nodes, digestive tract infections, loss of appetite, tuberculosis, shingles, headaches, emotional upset, dementia and other health problems. R. JARVIS & M. CLOSEN, *AIDS NUTSHELL*, *supra* note 2, at 14-17.

many as nine years or more.<sup>58</sup> That is a terribly long time to endure the death sentence of a positive HIV diagnosis, especially since medical science has succeeded thus far only in treating the symptoms of HIV/AIDS, at best in temporarily stabilizing and prolonging the death process. All of this raises the very same set of "difficult, indeed agonizing, questions" noted by Justice Scalia in the right-to-die context due to "the constantly increasing power of science to keep the human body alive for longer than any reasonable person would want to inhabit it."<sup>59</sup>

*B. Compulsory Disclosure Fails to Serve a Valid Medical or Public Health Purpose*

Is there any medical justification for compulsory HIV result disclosure to the individual tested? Compulsory disclosure could be justified if it led to behavior modification in the form of reduction of activities associated with a risk of HIV transmission. But there are important problems that diminish the persuasiveness of the argument that mandatory HIV disclosure will reduce HIV transmission.

First, with all of the media and public attention that has been directed to the HIV/AIDS epidemic generally, and to risk reduction specifically, members of the public are aware of HIV/AIDS and the routes of its transmission.<sup>60</sup> The Surgeon General's pam-

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58. SURGEON GENERAL'S REPORT, *supra* note 2, at 12; Lemp, Payne, Rutherford, Hessol, Winkelstein, Wiley, Moss, Chaisson, Chen, Feigal, Thomas & Werdegar, *Projections of AIDS Morbidity and Mortality in San Francisco*, 263 J. A.M.A. 1497 (1990). The survival time after diagnosis with AIDS may be as long as eight to ten years or longer, so that people might have HIV/AIDS disease for 20 years. R. JARVIS & M. CLOSEN, AIDS NUTSHELL, *supra* note 2, at 22-23; see also *HIV Prevalence Estimates and AIDS Case Projections for the United States: Report Based Upon a Workshop*, 39 MORBIDITY & MORTALITY WEEKLY REP. 1, 27 (1990) [hereinafter *HIV Prevalence*] (assuming a median 10-year incubation period for life-threatening HIV infection); Lemp, Payne, Neal, Temelso, Rutherford, *Survival Trends for Patients with AIDS*, 263 J. A.M.A. 402, 403 (1990) (reporting the longest survival time for people afflicted with AIDS as 8.1 years after diagnosis).

59. *Cruzan v. Director, Mo. Dep't of Health*, 110 S. Ct. 2841, 2859 (1990) (Scalia, J., concurring). This artificial extension of life has also been called "the tyranny of survival." Goodman, *Choosing Death: When Life Loses Its Meaning, Is Suicide Our Right?*, Chicago Tribune, Mar. 25, 1990, § 5, at 8, col. 1; see also *Brogdon v. State*, 781 P.2d 1370 (Alaska Ct. App. 1989) (diagnosis of HIV infection due to contaminated blood transfusion caused defendant to become extremely depressed, to drive his car at speeds in excess of 100 miles per hour and to collide with another vehicle, seriously injuring its driver).

60. There is substantial evidence that most of the population is aware of HIV/AIDS and its routes of transmission. A recent study found that 82% of male and 79% of female patients at an STD clinic knew that HIV could be transmitted through vaginal and anal intercourse and the exchange of intravenous drug needles. And 97% of male and 96% of female patients knew that the regular use of condoms can reduce the risk of