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# Lifting the Genealogical Veil: A Blueprint for Legislative Reform of the Disclosure of Health-Related Information in Adoption

D. Marianne Brower Blair

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# LIFTING THE GENEALOGICAL VEIL: A BLUEPRINT FOR LEGISLATIVE REFORM OF THE DISCLOSURE OF HEALTH- RELATED INFORMATION IN ADOPTION

D. MARIANNE BROWER BLAIR\*

*Many adopted children have failed to receive critically needed medical or psychiatric care because their adoptive parents were not given accurate and complete information about their medical and social history. Over the past decade, most state legislatures have enacted statutes that increase to some extent the amount of background information released to adoptive parents. In this Article, Professor Marianne Blair examines the goals of mandatory disclosure and the deficiencies in the majority of these statutes that prevent achieving the goal of greater disclosure of health-related information.*

*Professor Blair pays particular attention to the need to expand the scope of these statutes and the content of the information disclosed. Especially important is the analysis of appropriate and inappropriate methods of investigation and the impact of different methods on the privacy interests of the birth family. The difficult issues surrounding disclosure of a birth mother's HIV status are given special attention.*

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## I. INTRODUCTION

*Paul sat helplessly in the hospital room, watching his young son lying critically ill with kidney failure. The doctors, desperately seeking an explanation, stood questioning his wife intensely for information about her family medical history. Paul, who was adopted in infancy, had none to give.<sup>1</sup>*

*When they adopted Karen at age four, Sarah and Glenn were given only the slightest hint by the agency that she may have been mistreated. As Karen grew older, her behavior became increasingly violent and disruptive, necessitating lengthy therapy. She destroyed furniture, set a fire, and threatened to kill her two brothers. Ultimately Karen was institutionalized. Not until she reached adolescence did her parents learn, through litigation, that Karen had been severely physically and sexually abused as a child. This knowledge, and the recovery of photographs taken to document her severe injuries, proved to be the key to successful treatment. The opportunity to confront and come to terms with her abuse brought about a*

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1. Based on an account given under a different name by an adult adoptee at a panel discussion at a training conference for adoption social workers. Remarks in Panel Discussion at Conference on Genetic Family History: An Aid to Better Health of Adoptive Children (April 1984) [hereinafter Remarks in Panel Discussion], in WISCONSIN CLINICAL GENETICS CTR. & WAISMAN CTR. ON MENTAL RETARDATION & HUMAN DEVELOPMENT, GENETIC FAMILY HISTORY: AN AID TO BETTER HEALTH OF ADOPTIVE CHILDREN 26 (National Ctr. for Educ. in Maternal & Child Health 1984) [hereinafter GENETIC FAMILY HISTORY].

remarkable turnaround, and Karen was able to return home to her family.<sup>2</sup>

### A. Overview

Until recently, it has been the longstanding policy of most adoption agencies, public and private, to provide adoptive parents with little or no information regarding the medical and social history of an adopted child and the child's biological family.<sup>3</sup> Not only did state statutes not require such disclosure, they in fact often prohibited revealing this type of information without a court order and a showing of good cause.<sup>4</sup>

Although many times this policy was enforced with the best of intentions, these stories are just two examples of the countless lives that have been adversely affected, often tragically. Children with severe medical, psychological, and emotional problems often were placed with families unprepared to deal with their special needs.<sup>5</sup> Lack of information impaired diagnosis of children with physical or genetic disorders, causing expensive, unnecessary, and painful testing,<sup>6</sup> improper medical treatment, and, occasionally, permanent disability.<sup>7</sup> Children with severe sociopathic behavior failed to receive appropriate therapy for years, often resulting ultimately in their institutionalization, because their adoptive families and medical personnel lacked sufficient information to diagnose them properly.<sup>8</sup> In the meantime, some of these disturbed children vio-

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2. Based on an account of one adopted family that ultimately brought suit for access to their daughter's medical and social background information. The names have been changed. Telephone Interview with Neil Cogan, Associate Dean, Southern Methodist University College of Law (Aug. 8, 1990); Lisa Belkin, *Adoptive Parents Ask States for Help With Abused Young*, N.Y. TIMES, Aug. 22, 1988, at A1, B8 (discussing suit filed in Texas by adoptive parents and describing some of the problems their children have had).

3. See, e.g., Ginny Whitehouse, Remarks in Panel Discussion, *supra* note 1, at 20; Daniel Golden, *When Adoption Doesn't Work*, BOSTON GLOBE, June 11, 1989 (Magazine), at 16, 77-78; Rob Karwath, *Teenager's Adoptive Parents Sue*, CHI. TRIB., Dec. 29, 1989, § 2, at 1, 14.

4. See, e.g., John R. Ball & Gilbert S. Omenn, *Genetics, Adoption, and the Law*, in GENETICS AND THE LAW II 269, 275-77 (Aubrey Milunsky & George J. Annas eds., 1980); Frances S. Ryan, *The Legal Implications and Obligations of the Adoption Records Law of 1981*, in GENETIC FAMILY HISTORY, *supra* note 1, at 16 (noting that prior to passage of new Wisconsin disclosure law, neither child nor adoptive parent could obtain medical history after adoption was finalized, except by court order); Ann T. Lamport, Comment, *The Genetics of Secrecy in Adoption, Artificial Insemination and In Vitro Fertilization*, 14 AM. J.L. & MED. 109, 112 (1988). For an example of such statutes, see OKLA. STAT. ANN. tit. 10, § 60.17 (West 1987) (prohibiting disclosure), amended by OKLA. STAT. ANN. tit. 10, § 60.17(D) (West Supp. 1992) (providing for disclosure).

5. See *infra* notes 104-07, 112, 134-39 and accompanying text.

6. See *infra* notes 104-06, 114, 119-20 and accompanying text.

7. See *infra* notes 115-16, 122-23 and accompanying text.

8. See *infra* notes 104-11, 114-18 and accompanying text.

lently attacked siblings, adoptive parents, or other relatives, and many seriously harmed themselves by intentional self-mutilation or attempted suicide.<sup>9</sup> Families were beset with overwhelming medical bills for which the state gave no assistance, and were ineligible for the government subsidies they might otherwise have obtained had the condition been disclosed.<sup>10</sup> The emotional toll was staggering. Some adoptions were disrupted,<sup>11</sup> leaving the child with further psychological scars. Other members of the adoptive family also were devastated when these tragedies occurred, causing psychological problems for siblings and sometimes contributing to the divorce of the adoptive parents.<sup>12</sup>

Even when health problems do not appear in childhood, the absence of a medical history follows adoptees throughout their lives. Their future medical treatment and their ability to make informed reproductive choices are forever adversely affected.<sup>13</sup> The medical care of their offspring may also be impaired.<sup>14</sup> Similarly, when all lines of communication are broken, members of the original biological family lose access to medical information about the adoptee; this occasionally can pose grave consequences for their own reproductive choices and medical care.<sup>15</sup>

Part II of this Article therefore reviews the policy implications of nondisclosure and examine the factors that have prompted a recent wave of statutory reform. The purpose of this section is not merely historical, however, as the disclosure of health-related information is still the subject of vigorous debate.<sup>16</sup> Moreover, an in-depth understanding of the

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9. See *infra* notes 108-09 and accompanying text.

10. See *infra* notes 156-64 and accompanying text.

11. See *infra* note 112 and accompanying text. The term "disruption" as used in this Article includes both revocations and dissolutions that occur after finalization of the adoption and adoptive placements that are terminated prior to finalization. For a more complete discussion of the term "adoption disruptions," see RICHARD P. BARTH & MARIANNE BERRY, *ADOPTION AND DISRUPTION: RATES, RISKS AND RESPONSES* 20-22 (1988).

12. See *infra* notes 110-11 and accompanying text.

13. See *infra* notes 126-29 and accompanying text.

14. See *infra* note 239 and accompanying text.

15. See *infra* notes 253-57 and accompanying text.

16. Professor Joan Hollinger, of the University of Detroit College of Law and Reporter to the National Conference of Commissioners on Uniform State Laws (NCCUSL) on the Uniform Adoption Act, reports that during a discussion of an early draft of the revision to the Uniform Adoption Act in July, 1990 the provisions of the proposed act relating to disclosure of medical information generated a great deal of discussion and divergent views. Some of those present were totally opposed to any disclosure; at the other extreme, one commissioner advocated mandatory blood tests and DNA profiles of biological parents. Telephone Interview with Joan Hollinger, Reporter to the National Conference of Commissioners on Uniform State Laws on the Uniform Adoption Act (Nov. 5, 1990); see, e.g., Dirk Johnson, *Debate on Adoption is Focusing on Rights to See Family Histories*, N.Y. TIMES, Feb. 11, 1990, § 1, at 36.

arguments favoring disclosure illustrates the crucial need for statutes that effectively serve those goals.

During the past decade the vast majority of state legislatures have recognized the need for greater disclosure by enacting legislation allowing some medical information to be released to adoptive parents.<sup>17</sup> Close examination of these statutes, however, reveals that their content varies widely. Most are not sufficiently comprehensive to meet the needs of all who are affected, nor do they fully address the concerns that have been raised by social scientists and geneticists in recent literature. For example, some states make disclosure discretionary rather than mandatory;<sup>18</sup> a few still require a court order.<sup>19</sup> Many states' disclosure statutes do not apply to all adoptions.<sup>20</sup> Although all of the recent legislative efforts make information available to adoptive parents,<sup>21</sup> not all allow adult adoptees access to health information,<sup>22</sup> and few address the needs of others, such as descendants or biological siblings, for relevant genetic information.<sup>23</sup> Only a handful of states make health information available to adults whose parents' rights were terminated in juvenile court proceedings, but for one reason or another were never adopted.<sup>24</sup> The statutory description of the content of information to be collected and disclosed is rarely sufficiently comprehensive. Some states focus only on the medical history of the birth parents, others on the medical history of the child.<sup>25</sup> Very few insist that the medical and genetic history of relatives be included.<sup>26</sup>

In addition, state legislatures have not adequately prescribed effective methods of collection, retention, and disclosure of health-related in-

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17. During the past twelve years, only four states—Idaho, Mississippi, Nevada, and Rhode Island—and the District of Columbia have failed to enact legislation increasing the access of adoptive parents to some type of medical information.

18. See *infra* notes 178-80 and accompanying text.

19. See *infra* note 179 and accompanying text.

20. See *infra* notes 201-03, 213, 220 and accompanying text.

21. See *infra* note 177 and accompanying text.

22. See *infra* note 237 and accompanying text.

23. See *infra* notes 241, 259 and accompanying text.

24. See *infra* notes 246-50 and accompanying text.

25. For a list of states whose statutes omit reference to the child's medical history, see *infra* note 263. The following disclosure statutes refer only to the child's medical history: ARK. CODE ANN. § 9-9-505 (Michie Supp. 1991) (requiring only "written health, genetic and social history" of the child); COLO. REV. STAT. § 19-5-207 (Supp. 1991) (requiring written report including "physical and mental condition of the child" and the "child's family background"); MISS. CODE ANN. § 93-17-3 (Supp. 1990) (requiring "doctor's certificate showing the physical and mental condition of the child"); TENN. CODE ANN. § 36-1-114 (1991) (requiring only "information concerning the child's social and medical history").

26. See *infra* notes 288-89 and accompanying text.

formation. Assuring that trained professionals<sup>27</sup> assume responsibility for collection through personal interviews<sup>28</sup> is essential to obtaining accurate information. Specifying the scope of "reasonable efforts" to investigate is also critical.<sup>29</sup> In most states the time of disclosure to adoptive parents occurs far too late in the process.<sup>30</sup> Fewer than half of the states adequately address the need to collect, retain, and transmit to concerned parties medical and genetic information acquired subsequent to the adoption.<sup>31</sup> Including a provision for use immunity from civil and criminal liability must be given serious consideration.<sup>32</sup> Part III of this Article discusses these and other deficiencies in the current status of state legislation.

### B. Right to Privacy

Legislative efforts to regulate the collection and disclosure of such sensitive and personal information as medical and social history must be performed with careful attention to the privacy rights of birth parents, adoptees, and other members of their biological and adoptive families. This topic thus permeates each section of this Article. An individual's legal "right to privacy" broadly encompasses both a fundamental constitutional guarantee<sup>33</sup> and a collection of rights actionable in tort.<sup>34</sup> From

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27. See *infra* notes 334-38 and accompanying text.

28. See *infra* notes 445-47 and accompanying text.

29. See *infra* notes 343-409 and accompanying text.

30. See *infra* notes 463-70 and accompanying text.

31. See *infra* notes 454-58, 477-85 and accompanying text.

32. See *infra* notes 432-43 and accompanying text.

33. The concept of a constitutionally protected right to privacy is of course relevant to several different fields of federal constitutional law. In criminal proceedings, protection of an individual's privacy interests underlies Fourth Amendment restrictions on governmental search and seizure and the Fifth Amendment protection against self-incrimination. The First Amendment also protects privacy rights in speech and association. 2 RONALD D. ROTUNDA ET AL., TREATISE ON CONSTITUTIONAL LAW, SUBSTANCE AND PROCEDURE § 18.26, at 554 (1986). The constitutional right to privacy relevant to the issues raised in this Article, however, refers to a set of interests protected by the doctrines of due process and equal protection, *id.* § 18.26, at 555, which apply to state actions through the Fourteenth Amendment of the federal Constitution. See, e.g., *Eisenstadt v. Baird*, 405 U.S. 438, 443 (1972).

A fundamental constitutional right is one entitled to heightened protection under the doctrines of substantive due process and equal protection. 2 ROTUNDA et al., *supra*, § 15.7, at 79, § 18.1, at 316. When fundamental rights are impaired by state action, the state action must be necessary to achieve a compelling state interest in order to survive judicial scrutiny. *Id.* § 18.1, at 316; see *Zablocki v. Redhail*, 434 U.S. 374, 388 (1978). The United States Supreme Court repeatedly has recognized that privacy is a fundamental right. E.g., *Zablocki*, 434 U.S. at 383-84; *Griswold v. Connecticut*, 381 U.S. 479, 484-85 (1965); see 2 ROTUNDA et al., *supra*, § 15.7, at 79-82, § 18.27, at 558, § 18.28, at 564. Although this concept is broadly stated, the language primarily appears in cases considering infringement of personal autonomy, in such areas as marriage and procreation decisions. 2 ROTUNDA et al., *supra*, § 15.7, at 85. Fundamental-



both a theoretical and a pragmatic perspective, the scope of an individual's right to privacy eludes precise definition.<sup>35</sup> As judges and commentators struggle with this issue in myriad contexts, each employs his or her personal value system to reach a conclusion about the aspects of personhood that deserve protection from unwarranted intrusion. Moreover, each individual strikes a different balance in determining what constitutes a reasonable expectation of privacy in a society as complex and technologically advanced as ours.

The Supreme Court has described the constitutional right to privacy as the right to be free from unwanted<sup>36</sup> and "unwarranted governmental intrusion into matters fundamentally affecting a person."<sup>37</sup> More specifically, in *Whalen v. Roe*,<sup>38</sup> a unanimous decision, Justice Stevens identified at least two different privacy interests protected by the federal Constitution: "the interest in independence in making certain kinds of important decisions" and the "interest in avoiding disclosure of personal matters."<sup>39</sup>

Judicial development of the constitutional right to privacy has focused primarily on the first interest, the right of autonomy in personal decisionmaking.<sup>40</sup> Lower federal courts have recognized that an integral part of this interest is the right to bodily integrity, which includes the right to seek or refuse medical testing and treatment.<sup>41</sup> When state legislatures define the appropriate and permissible methods of obtaining med-

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rights strict-scrutiny analysis is not apparent in cases such as *Nixon v. Administrator of General Services*, 433 U.S. 425 (1977), and *Whalen v. Roe*, 429 U.S. 589 (1977), that acknowledge a privacy interest in nondisclosure of personal information.

State constitutions also may protect a right to privacy. See, e.g., Michele Schiffer, Comment, *Torts, Fraud in the Adoption Setting*, 29 ARIZ. L. REV. 707, 719 n.83 (1987) (discussing the right to privacy guaranteed by the Arizona Constitution).

34. W. PAGE KEETON ET AL., PROSSER AND KEETON ON THE LAW OF TORTS § 117, at 851 (5th ed. 1984); 2 ROTUNDA et al., *supra* note 33, § 18.26, at 554.

35. See LAURENCE H. TRIBE, AMERICAN CONSTITUTIONAL LAW § 15-1 (2d ed. 1988).

36. *Stanley v. Georgia*, 394 U.S. 557, 564 (1969).

37. *Eisenstadt*, 405 U.S. at 453.

38. 429 U.S. 589 (1977).

39. *Id.* at 599-600.

40. GEORGE J. ANNAS, THE RIGHTS OF PATIENTS 176 (1989); Walter J. Wadlington, *The Health Care Profession*, in 1 BIO-LAW 51, 61 (James F. Childress et al. eds., 1986). See generally 2 ROTUNDA et al., *supra* note 33, § 15.7, at 85, § 18.26, at 554-608 (discussing privacy as constitutional right).

41. See, e.g., *United States v. Charters*, 829 F.2d 479, 490-91 & nn.18-19 (1987), *aff'd on reh'g*, 863 F.2d 302 (4th Cir. 1988), *cert. denied*, 110 S. Ct. 1317 (1990); *Bee v. Greaves*, 744 F.2d 1387, 1392-93 (10th Cir. 1984); *Tune v. Walter Reed Army Medical Hosp.*, 602 F. Supp. 1452, 1456 (D.D.C. 1985); *Rasmussen ex rel. Mitchell v. Fleming*, 154 Ariz. 207, 214-15, 741 P.2d 674, 681-82 (1987); *In re A.C.*, 573 A.2d 1235, 1244-45 (D.C. 1990); *Superintendent of Belchertown State Sch. v. Saikewicz*, 373 Mass. 728, 747, 370 N.E.2d 417, 424 (1977); *In re Conroy*, 98 N.J. 321, 346, 355, 486 A.2d 1209, 1222-23, 1229 (1985).

ical information from birth parents and other relatives they must consider this facet of the right to privacy. In particular, should biological relatives be compelled to undergo medical, genetic, or psychological testing?<sup>42</sup> Adoptees have asserted contrasting reliance upon the privacy doctrine by arguing, to date unsuccessfully, that their right to privacy, along with other constitutional rights, entitles them and their adoptive parents to view medical history records in order to make better decisions about their own medical treatment and reproduction.<sup>43</sup>

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42. See *infra* notes 410-19 and accompanying text.

43. Adoptees and adoptive parents have argued in a series of lawsuits that adequate medical and social history are so vital to the psychological well-being and health of both adoptees and their descendants that their entitlement to this information should be treated as a fundamental right. They assert that adoptees have a due process liberty interest in appropriate medical care and treatment, which is inhibited by withholding medical and social history. See *Griffith v. Johnston*, 899 F.2d 1427, 1438-39 (5th Cir. 1990). These litigants also have alleged that the right to know one's identity and heritage is akin to the rights of family privacy previously recognized by the Supreme Court. See *Alma Soc'y, Inc. v. Mellon*, 601 F.2d 1225, 1231 (2d Cir. 1979); *In re Roger B.*, 84 Ill. 2d 323, 327, 418 N.E.2d 751, 753 (1981). Adoptees also have asserted constitutional entitlement to background information under an equal protection theory, contending they are treated differently than nonadopted children, see, e.g., *Mellon*, 601 F.2d at 1233; *Mills v. Atlantic City Dep't of Vital Statistics*, 148 N.J. Super. 302, 314, 372 A.2d 646, 652 (Super. Ct. Ch. Div. 1977), or, alternatively, that they are treated differently than children in state custody, whose medical caretakers have the benefit of medical history, see *Griffith*, 899 F.2d at 1441. They also have relied on the First Amendment right to receive important information, see *In re Maples*, 563 S.W.2d 760, 762 (Mo. 1978); *Mills*, 148 N.J. Super. at 312, 372 A.2d at 652, and the Thirteenth Amendment, claiming that "abolition practically of the parental relation" is an incident of slavery, *Mellon*, 601 F.2d at 1236-37. Several commentators support some or all of these positions. See, e.g., Carolyn Burke, Note, *The Adult Adoptee's Constitutional Right to Know His Origins*, 48 S. CAL. L. REV. 1196, 1220 (1975) (First Amendment right to information and right to privacy); Carol Gloor, Comment, *Breaking the Seal: Constitutional and Statutory Approaches to Adult Adoptees' Right to Identity*, 75 NW. U. L. REV. 316, 343-44 (1980) (fundamental right); Barbara Prager & Stanley A. Rothstein, Note, *The Adoptee's Right to Know His Natural Heritage*, 19 N.Y. L.F. 137, 137-39 (1973) (equal protection); Nancy Sparks, Note, *Adoption: Sealed Adoption Record Laws—Constitutional Violation or a Need for Judicial Reform?*, 35 OKLA. L. REV. 575, 583-89 (1982) ("Preventing access to information about an adoptee's genetics may hamper the decisionmaking process concerning such things as procreation and contraception."). But see Paul J. Tartanella, Note, *Sealed Adoption Records and the Constitutional Right of Privacy of the Natural Parent*, 34 RUTGERS L. REV. 451, 488-90 (1982) (suggesting continued discussion of adoptee rights).

Most disclosure advocates treat the right to background information and the right to the identity of the birth parents as inextricably interwoven. The courts consistently have refused to recognize a constitutional right to information, yet in each case except *Griffith* the court's discussion focused entirely on the right to the birthparent's identity. In several decisions it was specifically noted that the adoptee had been given nonidentifying background information from the agency's files. See *Mellon*, 601 F.2d at 1233; *In re Roger B.*, 84 Ill. 2d at 329-30, 418 N.E.2d at 755-56; *In re Dixon*, 116 Mich. App. 763, 766-67, 323 N.W.2d 549, 551-52 (1982); *In re Maples*, 563 S.W.2d at 766; *Mills*, 148 N.J. Super. at 317-18, 372 A.2d at 654; *In re Assalone*, 512 A.2d 1383, 1390 (R.I. 1986); *Bradley v. Children's Bureau*, 275 S.C. 622, 625, 274 S.E.2d 418, 422 (1981).

In *Griffith v. Johnston* adoptive parents and their children sued the State of Texas seeking

Constitutional restrictions on the collection, retention, and disclosure of personal information have received far less attention from the courts. In 1977 the Supreme Court acknowledged in *Whalen v. Roe* "the threat to privacy implicit in the accumulation of vast amounts of personal information in computerized data banks or other massive government files," and recognized that the duty to avoid unwarranted disclosure of this information "arguably has its roots in the Constitution."<sup>44</sup> Nevertheless, the *Whalen* Court upheld the constitutionality of a state statute requiring that copies of all prescriptions for certain drugs<sup>45</sup> be filed with the state health department, finding that the program as administered did not pose a sufficiently grievous threat either to the patient's interest in nondisclosure of private information or in autonomy of personal decisionmaking.<sup>46</sup> That same year, in *Nixon v. Administrator of General Services*,<sup>47</sup> the Court again recognized a constitutionally protected privacy interest in avoiding disclosures of a personal nature, but rejected President Richard M. Nixon's privacy challenge to a federal law authorizing the government to seize and screen all of his documents and tape recordings.<sup>48</sup>

Since 1977 the Supreme Court has not directly addressed the constitutional limitations upon governmental collection and disclosure of information, except in the context of Fourth and Fifth Amendment restrictions in criminal proceedings.<sup>49</sup> Scholars have called for greater

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both disclosure of nonidentifying medical information in their files and services for the children. The United States Court of Appeals for the Fifth Circuit held that they had failed to state a claim under either the Due Process or Equal Protection Clauses of the Fourteenth Amendment. *Griffith*, 899 F.2d at 1441. The court noted, however, that their request for the information was moot because during the litigation Texas had passed legislation providing adoptive parents a right to the information requested. *Id.* at 1434 n.4. Thus, the issue was before the court in the context of a claim for ameliorative services.

44. *Whalen v. Roe*, 429 U.S. 589, 605 (1977) (constitutional challenge to 1972 New York statute requiring that for certain drugs copies of prescriptions containing the name of the prescribing physician, pharmacy, drug, dosage, and name, address, and age of the patient be filed and recorded with the State Health Department).

45. The New York Legislature established a separate category of drugs considered to have legitimate medical uses, but to be the most dangerous in terms of potential for abuse. This category includes opium and opium derivatives, cocaine, methadone, amphetamines, and methaqualone. *Id.* at 592-93.

46. *Id.* at 600.

47. 433 U.S. 425 (1977).

48. *Id.* at 457. Because the Act ordered that items of a personal or private nature were to be returned to President Nixon, the Court found that any privacy interest in avoiding the screening process itself was outweighed by the important public interest in preserving the vast majority of the materials, which concerned official conduct of Nixon's presidency and for which he lacked a reasonable expectation of privacy. *Id.* at 465.

49. See 2 ROTUNDA et al., *supra* note 33, § 18.30, at 600-01. For an earlier case in which the Supreme Court confronted a constitutional privacy challenge to a state's recordkeeping

judicial attention to defining a constitutional limitation emanating from a Fourteenth Amendment right to privacy.<sup>50</sup> At present, however, the parameters of this limitation are extremely ill-defined.

When they attempt to regulate the collection of medical and social history and the scope of permissible disclosure, state legislatures must consider the constitutional dimension of the interests of adoptees and their families in controlling access to personal information. To what extent should the adoptee's descendants have access to this information?<sup>51</sup> Should investigators be authorized to obtain medical records of birth parents or other relatives without their consent?<sup>52</sup> Is it an invasion of a birth mother's privacy to conduct diagnostic tests upon the infant that may disclose her own medical status?<sup>53</sup> This amorphous second branch of the constitutional right to privacy affects these and other issues<sup>54</sup> addressed in this Article.

Judges have paid far more attention to the interest in protecting personal information in the context of a developing body of tort law. Throughout the last century state courts have recognized liability for violations of a common-law right to privacy.<sup>55</sup> Regarded initially as "the right to be let alone,"<sup>56</sup> the right now encompasses several distinct causes

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regulations for abortion, see *Planned Parenthood v. Danforth*, 428 U.S. 52, 80-81 (1976). In *Danforth* the Court again upheld the recordkeeping scheme, holding that the requirements were "reasonably directed to the preservation of maternal health" and properly respected "a patient's confidentiality and privacy." *Id.*

In another case concerning relief for invasion of privacy, parents of schoolchildren sued a congressperson, the Public Printer, and the Superintendent of Documents for invasion of privacy resulting from dissemination of a congressional report identifying certain students in derogatory contexts. The Court held that congressional immunity did not apply to the Printer or Superintendent and remanded the case for a determination of the validity of the cause of action and possible defenses. *Doe v. McMillan*, 412 U.S. 306, 324-25 (1973).

50. 2 ROTUNDA et al., *supra* note 33, § 18.30, at 605; TRIBE, *supra* note 35, § 5-24, at 399-400.

51. See *infra* notes 239-45 and accompanying text.

52. See *infra* notes 363-72 and accompanying text.

53. See *infra* notes 404-09 and accompanying text.

54. See *infra* notes 288-91 (access to records of biological relatives), 410-19 (mandatory testing of biological parents or relatives), 421-31 (sanctioning parents for nondisclosure).

55. KEETON et al., *supra* note 34, § 117, at 849-50. The origin of recognition of tort liability for invasion of a right to privacy is often traced to a famous article by Samuel D. Warren and Louis D. Brandeis, *The Right to Privacy*, 4 HARV. L. REV. 193, 195 (1890). KEETON et al., *supra* note 34, § 117, at 849; 2 ROTUNDA et al., *supra* note 33, § 18.26, at 554 n.1. Allegedly the first case to afford recovery on a right-of-privacy cause of action was an unreported New York decision, *Manola v. Stevens* (N.Y. Sup. Ct. 1890), discussed in N.Y. TIMES, June 15, 18, 21, 1890. KEETON et al., *supra* note 34, § 117, at 850 n.10.

56. KEETON et al., *supra* note 34, § 117, at 849; Ball & Omenn, *supra* note 4, at 271. The phrase is attributed to Judge Cooley, who used it in THOMAS M. COOLEY, A TREATISE ON THE LAW OF TORTS OR THE WRONGS WHICH ARISE INDEPENDENT OF CONTRACT 29 (Chicago, Callaghan & Co. 2d ed. 1888). KEETON et al., *supra* note 34, § 117, at 849 & n.3.

of action, including public disclosure of private facts.<sup>57</sup> Several courts have held that protection of a patient's privacy is a legal duty, as well as an ethical one, and that unauthorized disclosure of a patient's medical records constitutes an actionable invasion of the right to privacy.<sup>58</sup>

Closely related is judicial endorsement of liability for breach of the duty of medical confidentiality, now recognized in some jurisdictions as a separate tort.<sup>59</sup> The duty of medical confidentiality prohibits physicians and other medical personnel from revealing information they acquire about their patients in the course of the patients' treatment.<sup>60</sup> Originally viewed as a professional duty mandated by the ethical codes of certain health-care professions,<sup>61</sup> the existence of a legal duty giving rise to tort liability now often derives from the statutory physician-patient testimonial privilege, medical licensing statutes, or professional regulations.<sup>62</sup> The underlying rationale for the duty of medical confidentiality is twofold: first, protection of the patient's right to determine who has access to personal information, and second, the concern that patients will be less likely to seek medical treatment or provide complete and accurate infor-

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57. KEETON et al., *supra* note 34, § 117, at 851, 856-63.

58. See, e.g., *Horne v. Patton*, 291 Ala. 701, 708-09, 287 So. 2d 824, 830 (1974); *Valencia v. Duval Corp.*, 132 Ariz. 348, 350, 645 P.2d 1262, 1263 (Ct. App. 1982); *Vassiliades v. Garfinckel's Brooks Bros.*, 492 A.2d 580, 591 (D.C. 1985); *Acosta v. Carey*, 365 So. 2d 4, 5 (La. Ct. App. 1978); *Bratt v. International Business Machs.*, 392 Mass. 508, 522-23, 467 N.E.2d 126, 136-37 (1984); *Prince v. St. Francis-St. George Hosp. Inc.*, 20 Ohio App. 3d 4, 5, 484 N.E.2d 265, 266-67 (1985); see also *Logan v. District of Columbia*, 447 F. Supp. 1328, 1335-36 (D.D.C. 1978) (refusing to recognize cause of action for breach of the confidentiality of the physician-patient relationship but recognizing the validity of the invasion of privacy claim); *Judy E. Zelin, Annotation, Physician's Tort Liability for Unauthorized Disclosure of Confidential Information About Patient*, 48 A.L.R. 4th 668, 680-91 (1986) (summarizing cases in which courts considered the tort liability of doctors for unauthorized disclosure of confidential information).

59. *Humphers v. First Interstate Bank*, 298 Or. 706, 717, 696 P.2d 527, 533 (1985); *Zelin*, *supra* note 58, at 679.

Although both a claim for invasion of privacy based upon release of medical information and a claim for breach of the duty of medical confidentiality can arise from wrongful disclosure of health-related information, some jurisdictions recognize the different parameters of each claim. Breach of medical confidentiality need not involve information considered personal or private to the same degree as is required for a claim for invasion of privacy. Breach of medical confidentiality requires that the defendant obtain the disclosed information in a confidential relationship, whereas, theoretically, if a disclosure otherwise qualifies as an invasion of privacy, no confidential relationship with the wrongdoer is necessary to impose liability. *Id.*

60. Candace C. Gauthier, *HIV Testing and Confidentiality*, 2 *BIOETHICS* S:349, S:351 (James F. Childress & Ruth D. Gaare eds., Mar.-Apr. 1990 Special Section); see *ANNAS, supra* note 40, at 176.

61. *ANNAS, supra* note 40, at 176 (noting that both the American Medical Association's Principles of Ethics and the American Nurses' Association Code mandate maintenance of confidentiality); *Gauthier, supra* note 60, at S:351.

62. *Humphers*, 298 Or. at 718-19, 696 P.2d at 534.

mation to medical personnel without an assurance of confidentiality.<sup>63</sup> The duty has many exceptions, however. For example, courts have recognized that confidentiality may be violated to prevent harm to the patient, to prevent harm to an identifiable third party, or to protect the public health.<sup>64</sup>

While tort liability can, of course, be abrogated by statute, legislatures must contemplate the policy considerations underlying the tort doctrine regarding invasion of privacy and violation of medical confidentiality in determining the appropriate extent of collection efforts and the proper scope of disclosure.<sup>65</sup>

Widespread recognition of certain conditions that merit a particularly high degree of privacy protection has prompted the enactment of specific nondisclosure statutes. These statutes typically prohibit releasing information regarding persons who have been tested for or who have contracted certain sexually transmitted diseases, such as acquired immune deficiency syndrome (AIDS) and syphilis.<sup>66</sup> The tremendous discrimination in housing, employment, education, and other aspects of life encountered by people with AIDS in particular,<sup>67</sup> merits special attention to the application of the recommendations made throughout this Article to information regarding human immunodeficiency virus (HIV) testing or treatment. The Article therefore examines this topic in a separate section.<sup>68</sup> States must carefully consider the extent to which exceptions to these specific nondisclosure statutes should be created to implement the collection and disclosure of health-related information in adoption.<sup>69</sup>

A final point worth emphasizing is the central role that interest-bal-

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63. Gauthier, *supra* note 60, at S:351.

64. Ball & Omenn, *supra* note 4, at 273; Gauthier, *supra* note 60, at S:352.

65. See *infra* notes 244-45, 359-61 and accompanying text.

66. See MICH. COMP. LAWS ANN. § 333.5131(8) (West Supp. 1991) (stating that person who violates HIV nondisclosure statute is liable in a civil action for actual damages or \$1,000, whichever is greater, and costs and reasonable attorney fees); MO. ANN. STAT. § 191.656(6) (Vernon Supp. 1991) (imposing civil liability for violation of HIV nondisclosure statute).

67. One physician reports that disclosure of a positive HIV test result caused his patient to lose employment, housing, and insurance. Within 10 days after testing, the life he had known for 10 years was in ruins. Ronalow Sherer, *Physician's Use of the HIV Antibody Test: The Need for Consent, Counseling, Confidentiality, and Caution*, 259 JAMA 264, 264 (1988); see, e.g., Gauthier, *supra* note 60, at S:361; Larry Gostin, *Public Health Law: Current Problems and Future Remedies*, 1 BIOLAW R:31, R:47 (James F. Childress et al. eds., July Supp. 1989).

68. See *infra* notes 373-93 and accompanying text; see also notes 404-09 and accompanying text (discussing privacy implications of conducting tests upon child that reveal HIV status of the birth mother).

69. See *infra* notes 399-409 and accompanying text.

ancing plays in determining whether an individual's constitutional, common-law, or statutory right to privacy has been impaired. In both the constitutional and tort doctrines of privacy, a determination that information is highly sensitive or that a given action will impair an individual's decisionmaking ability does not automatically trigger judicial protection. The Supreme Court has repeatedly observed that the right to privacy is not absolute.<sup>70</sup> When state action impairs decisionmaking about fundamental aspects of one's life, the action will withstand judicial scrutiny if it is found to be necessary to achieve a compelling state interest.<sup>71</sup> Courts have subjected state-mandated collection, retention, and disclosure of personal information to a less rigorous constitutional review. Tribunals have upheld state statutory schemes when the collection, retention, and specified use of the data served reasonable public interests and when the statute included sufficient procedures to guard against unwarranted disclosure.<sup>72</sup> Similarly, tort law recognizes a cause of action for disclosure of private facts only when the public has no legitimate interest in the information.<sup>73</sup> The law creates exceptions to the doctrine of medical confidentiality for situations in which substantial counterbalancing interests exist, such as the protection of third parties or the public.<sup>74</sup> Even specific nondisclosure statutes provide for disclosure under certain circumstances.<sup>75</sup>

Recognizing the need for more extensive collection and disclosure of health-related information in adoption thus requires analyzing many complex issues and weighing the substantial interests of the many individuals affected by adoption. The line-drawing is sometimes not easy and surely will remain subject to vigorous debate. This Article suggests where these lines should be drawn; equally as important, however, it attempts to stimulate that debate and draw renewed attention to the diffi-

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70. See, e.g., *Zablocki v. Redhail*, 434 U.S. 374, 388 (1978); *Roe v. Wade*, 410 U.S. 113, 154 (1973); see also *In re A.C.*, 573 A.2d 1235, 1245-46 (D.C. 1990) (summarizing precedent establishing that the right to accept or reject medical treatment is not absolute).

71. See, e.g., *Zablocki*, 434 U.S. at 388; see also 2 ROTUNDA et. al, *supra* note 33, § 18.1, at 316 (discussing judicial scrutiny of fundamental rights).

72. *Nixon v. Administrator of Gen. Servs.*, 433 U.S. 425, 458, 462-65 (1977); *Whalen v. Roe*, 429 U.S. 589, 598, 602, 605-06 (1977).

73. RESTATEMENT (SECOND) OF TORTS § 652D (1977) (providing that one who gives publicity to a matter concerning the private life of another is subject to liability to the other for invasion of his privacy if the matter publicized is of a kind that (a) would be highly offensive to a reasonable person, and (b) is not of a legitimate concern to the public); KEETON et al., *supra* note 34, § 117, at 857; see *Horne v. Patton*, 291 Ala. 701, 709, 287 So. 2d 824, 830 (1974).

74. Ball & Omenn, *supra* note 4, at 272-73.

75. See, e.g., ILL. ANN. STAT. ch. 111½, para. 7309 (Smith-Hurd Supp. 1991) (HIV nondisclosure statute); WASH. REV. CODE ANN. § 70.24.105 (West Supp. 1991) (same).

cult issues that have not yet been addressed adequately in the majority of adoption disclosure statutes now on the books.

## II. THE DISCLOSURE DEBATE

An understanding of the contours of the debate over disclosure of health-related information is critical to assessing the precise scope and methodology of current disclosure statutes. This section therefore summarizes the principal arguments of opponents and proponents of disclosure, providing a framework for more detailed analysis of the appropriate extent and implementation of disclosure in Part III.

### A. *Traditional Concerns About Full Disclosure*

For most of the twentieth century<sup>76</sup> adoption agencies commonly gave very limited information about the medical and social background of a child and the child's biological family to adoptive parents.<sup>77</sup> One explanation for this approach was philosophical. Adoption aimed to provide a fresh start, severing all ties with the biological family and building the illusion that the child was born into the adoptive family.<sup>78</sup> Adoptive parents and children were matched by physical characteristics,<sup>79</sup> and birth certificates were changed to indicate that the adoptive

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76. The history of adoption in America indicates that even before the recent wave of reform in the 1980s, secrecy has not always been the norm. Prior to 1851 adoption was a private agreement, like a conveyance of real estate, that was authenticated by making a public record and, in some instances, undergoing a proceeding for a name change. Ruth-Arlene W. Howe, *Adoption Practice, Issues, and Laws 1958-83*, 17 FAM. L.Q. 173, 175-76 (1983); Sanford N. Katz, *Rewriting the Adoption Story*, 5 FAM. ADVOC., Summer 1982, at 9, 9. In 1851 Massachusetts passed the first adoption statute that established judicial supervision over adoptions. Katz, *supra*, at 9. Until the 1920s, when confidentiality statutes were enacted by many states, adoptions were often open. It was a common practice for the birth mother to stay with the adoptive family during pregnancy, or to be chosen by the birth mother's family. Newspapers routinely reported details of adoption proceedings during the late nineteenth century. ADOPTION LAW AND PRACTICE §§ 1.03[4], 13.01[1][b] (Joan H. Hollinger ed., 1988); LINCOLN CAPLAN, AN OPEN ADOPTION 85 (1990).

77. See, e.g., ARTHUR D. SOROSKY ET AL., THE ADOPTION TRIANGLE 35-36 (1978); Golden, *supra* note 3, at 77; Karwath, *supra* note 3, at 12 (David Schneidman, spokesperson for the Illinois Department of Children and Family Services, stated that prior to the enactment of Illinois' disclosure law in 1985, the conventional wisdom of adoption agencies was that adopted children and parents were better off not knowing background information.).

78. SOROSKY et al., *supra* note 77, at 38; Katz, *supra* note 76, at 9, 10; Lampert, *supra* note 4, at 110; Golden, *supra* note 3, at 77 (noting that the fresh start philosophy was fostered by fact that adoptions during the mid-twentieth century occurred primarily with infants, and were considered a rebirth; thus only a minimum of background information was provided to new parents).

79. Katz, *supra* note 76, at 9.



parents were the birth parents.<sup>80</sup> Emphasizing the child's biological ties was inconsistent with this philosophy.

Concrete concerns related to the child's welfare also underlay limited disclosure. Caseworkers' fear that a child might not otherwise be placed<sup>81</sup> was a major factor militating against full disclosure. Richard Hochstra, director of Michigan's public adoption services, explained: "You want the best for these children. So it is easy to withhold information, not in a malicious sense, but in the sense that you are highlighting some of the best in these children, and you tend to leave out some of the problems."<sup>82</sup> Selective disclosure of this nature has been a particular problem for many families who adopted older children from state agencies, only to discover subsequently a long history of psychiatric disorders.<sup>83</sup>

Another concern is the serious potential for stigmatization of the child—a prospect harmful in many respects. Knowledge of the existence of a familial genetic disorder may limit placement options for a child, possibly precluding homes that would otherwise be the best placement, even though the child may never develop the disease.<sup>84</sup> When the child is adopted, knowledge of genetic disorders, a history of parental mental illness or drug use, or other factors perceived as negative in a child's background could affect adversely the attitude of adoptive parents or other relatives toward the child, impairing these relationships and the child's development.<sup>85</sup> Apart from the effects of specific information, social scientists previously coined the phrase "the bad blood syndrome" to describe some adoptive parents' general anxiety that hereditary factors might produce negative behavior.<sup>86</sup> More specific knowledge of negative

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80. SOROSKY et al., *supra* note 77, at 38. This is still a common practice. See, e.g., OKLA. STAT. ANN. tit. 10, § 60.18 (West 1987).

81. See KATHERINE A. NELSON, ON THE FRONTIER OF ADOPTION: A STUDY OF SPECIAL NEEDS ADOPTIVE FAMILIES 87 (1985) (study conducted by Child Welfare League of America of 177 families who adopted 257 children classified as "special needs" children).

82. Dianne Klein, "Special" Children, Dark Past Can Haunt Adoptions, L.A. TIMES, May 29, 1988, § 1, at 1, 33.

83. Belkin, *supra* note 2, at B8; Golden, *supra* note 3, at 77-78; Klein, *supra* note 82, at 1, 33.

84. Norman Fost, *Disclosing Genetic Information to Adoptive Parents: Ethical Considerations*, in GENETIC FAMILY HISTORY, *supra* note 1, at 50, 51.

85. Rita B. Black, *Genetics and Adoption: A Challenge for Social Work*, in SOCIAL WORK IN A TROUBLED WORLD: SEVENTH NASW SYMPOSIUM 199-202 (Miriam Dinerman ed., 1981); Fost, *supra* note 84, at 50, 51; Gilbert S. Omenn et al., *Genetic Counseling for Adoptees at Risk for Specific Inherited Disorders*, 5 AM. J. MED. GENETICS 157, 162 (1980).

86. Black, *supra* note 85, at 201-02. Black notes that until recently it was the prevailing view in the adoption field that genetic factors played little role in influencing behavior, a view that was communicated to adoptive parents. Nevertheless, studies of adoptive families indicate that many adoptive parents retained an exaggerated fear of hereditary influence. See also

factors could exacerbate this problem. Revealing newly discovered information after the adoption could negatively affect an unstable family, cause parental feelings or actions of rejection, or even provoke a revocation.<sup>87</sup>

A further concern is the impact of "negative" knowledge on the adoptee's self-image. Aside from the effects of others' perceptions, an adoptee could develop a negative sense of identity or predestiny by acquiring genetic or social information about ancestors that the adoptee perceives as undesirable.<sup>88</sup> Knowledge may create tremendous anxiety about a genetic disorder that may not have been transmitted to this adoptee, or may not create symptoms until much later.<sup>89</sup> Genetic counselors have devised the term "shattered self-adequacy syndrome" to describe the acute and chronic stress that diagnosis of a genetic disorder creates.<sup>90</sup> Making such information available to adopted children means that adoptees will not be spared that stress, and may not have the benefit of the support that would be available to unadopted persons from family members who are also at risk.

Others have posited a financial argument. Disclosure of medical information to adoptive parents and adult adoptees facilitates access to that information by insurance companies, who may use it to screen out adoptees from coverage of life or health insurance due to genetic risks that would not otherwise be known.<sup>91</sup>

Opponents of disclosure also rely heavily on their expressed concern for the privacy and anonymity of birth parents and relatives.<sup>92</sup> Such critics argue that extensive release of medical and social background information, even with names and addresses redacted, could facilitate tracing efforts by adoptees to find birth parents or relatives.<sup>93</sup> Social and medical history could also contain sensitive or potentially embarrassing revela-

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NATIONAL COMMITTEE FOR ADOPTION, 1989 ADOPTION FACTBOOK 205-06 (1989) [hereinafter ADOPTION FACTBOOK] (discussing myth of a negative "adopted child syndrome").

87. Omenn et al., *supra* note 85, at 162-63.

88. See Fost, *supra* note 84, at 51.

89. Omenn et al., *supra* note 85, at 162.

90. Black, *supra* note 85, at 199-200.

91. Fost, *supra* note 84, at 53-54. When adoptive parents have information of genetic risks, they may be required to report the risks on insurance application forms.

92. See SOROSKY et al., *supra* note 77, at 50; Lampert, *supra* note 4, at 123; Timothy N. O'Connell, Note, *S.B. 340: Disclosure of Social and Medical History of the Biological Parents of an Adopted Child*, 4 U. DAYTON L. REV. 533, 535, 537 (1979) (citing critics of Ohio's newly-enacted nondisclosure statute who opposed the statute on the grounds that the privacy of the biological parents was not adequately protected); Johnson, *supra* note 16, at 36. See generally Omenn et al., *supra* note 85, at 162 (discussing importance of confidentiality of parties to adoption in evaluating disclosure of supplemental medical information).

93. O'Connell, *supra* note 92, at 537.

tions concerning such topics as mental illness, substance abuse, criminal behavior, sexually transmitted diseases, prior pregnancies, or abortions. In two states, Alaska and Kansas, the adoptee has a right to identifying information upon reaching majority;<sup>94</sup> in other states the adoptee may find the birth parent through a registry<sup>95</sup> or other consensual statutory procedures.<sup>96</sup> Identity disclosure down the road creates the possibility that sensitive information could be revealed by the adoptee to others not chosen by the birth parent or biological relative. In a similar vein, it has been argued that birth mothers now may be motivated to seek independent rather than agency adoption to avoid intrusive questioning,<sup>97</sup> and that mandating extensive questioning could prompt them to choose other options, such as abortion.<sup>98</sup>

Finally, some commentators have raised the specter that access to medical information will promote searches by adoptive parents for "the perfect child."<sup>99</sup> One article hypothesizing about a variety of evils of genetic testing speculated that adoption "brokers" might use them to "probe the genetic history of babies."<sup>100</sup> Adoptive parents, critics declare, must assume the same risks as biological parents.<sup>101</sup>

### *B. The Tragedy of Nondisclosure and Arguments for Transmission of Health-Related Information*

Despite the concerns outlined above, experts in the adoption field now agree that medical and social background information should be given to adoptive parents.<sup>102</sup> The Child Welfare League of America, a national affiliation of adoption agencies and one of the foremost Ameri-

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94. ADOPTION LAW AND PRACTICE, *supra* note 76, § 13.01[3], at 13-21 (Supp. 1991).

95. *Id.* § 13.01[3][b], at 13-39 (Supp. 1991) (observing that at least 21 states have enacted some form of mutual consent registry to assist with consensual meetings between those involved in adoptions, most typically adult adoptees and their biological parents or siblings).

96. *Id.* § 13.01[3][c], at 13-39 (Supp. 1991) (stating that 16 states have adopted search-and-consent statutes authorizing a public or private agency or a trained intermediary to assist in locating biological parents to determine whether they will consent to disclosure of identity or to meeting). Many states also have statutory provisions allowing release of identifying information by court order for good cause. *Id.* § 13.01[3][d] (Supp. 1991).

97. Johnson, *supra* note 16, at 36 (quoting William Pierce, President of the National Committee for Adoption).

98. Lamport, *supra* note 4, at 123.

99. See Kay Kitzman, Remarks in Panel Discussion, *supra* note 1, at 24 (Kitzman is an adoptive mother).

100. Dorothy Nelkin & Laurence Tancredi, *Threats to Privacy in Biological Testing*, S. F. CHRON., Feb. 7, 1990, § Z-1, at 8.

101. See Fost, *supra* note 84, at 52-53.

102. ADOPTION LAW AND PRACTICE, *supra* note 76, § 13.01[1][c], at 13-10 to -11; SOROSKY et al., *supra* note 77, at 36. For a summary of testimony by adoption experts stating that it is the policy of their agencies to provide nonidentifying background information, see

can authorities on adoption standards, endorses full disclosure of this information in its guidelines for adoption professionals.<sup>103</sup>

Backes v. Catholic Family & Community Servs., 210 N.J. Super. 186, 189, 191, 192, 509 A.2d 283, 287, 289, 291 (Super. Ct. Ch. Div. 1985).

The recommendation of psychologists who deal with disturbed children is identical. "[A]gencies should fully disclose to adoptive parents the background of the child and fully prepare prospective parents if they are to receive an unattached child." KEN MAGID & CAROLE A. MCKELVEY, *HIGH RISK* 153 (1987).

103. SOROSKY et al., *supra* note 77, at 36 (observing that the Child Welfare League of America has recommended since 1971 that adoptive parents be given nonidentifying medical and social background information). Current Child Welfare League Standards provide:

#### 4.13 Discussion of Information about the Child

Except as limited by statute, special circumstances, or the wishes of the parties to the adoption, adoptive parents should be given full disclosure of information about the birth parents and the child to be adopted. (3.1-3.6)

This information should include:

- Developmental history—birth history, weight and height, feeding and sleeping habits of infants, and deviation from normal development of the older child that may affect current or future functioning (3.1, 3.2)
- Level of current development (3.2, 3.3, 3.5)
- Personality and temperament—ways of responding and relating to people, sensitivities, likes and dislikes, special aptitudes and interests, preferred method of being cared for (3.1)
- Medical data—immunizations, illnesses, handicapping conditions; any extended or expensive medical care that may be needed, probable length of medical care, probable expenses for adoptive parents and possible subsidies for the care; and extent or limitation of activities and/or interference with educational, social, or vocational functioning and achievements that might be expected (3.2, 5.10, 6.27, 7.6)
- Known hereditary and other conditions—problems that may either appear later or adversely affect future development (the advice of appropriate consultants is important both to determine scientifically any risks and to know how to interpret them) (3.2, 3.4, 6.27)
- Prior placement history, if any. (3.1)

Both the adoptive family and the physician caring for the child after placement should be provided with a medical history in writing. The adoptive parents should be asked to keep the agency informed of newly discovered medical or genetic information of importance to the health of the birth parents or the development of their other children. The agency should advise the adoptive parents that the birth parents have also been asked to add any newly discovered significant family history that can affect the future development of the adopted child.

#### 4.14. Information about birth parents

Adoptive parents should be provided with information about the birth parents that they would need in order to have an understanding of the birth parents and the reasons for the placement of the child for adoption and to feel comfortable later in addressing the child's questions about his or her birth parents.

Information about the birth parents is helpful for the adoptive parents to know and be able to share with the child throughout childhood. Examples of descriptive information include age, physical characteristics, special abilities or interests, education, temperament, adjustment, and capacity for relationships. (4.15)

The reasons for this shift can best be appreciated by examining a case history that vividly illustrates the disastrous impact of nondisclosure on many families. Lisa, a blonde, blue-eyed six year old, was placed for adoption with Joan and Bob after four short visits to their home.<sup>104</sup> They were told she had been physically abused by her mother as a young child, and that she was removed from a foster home, where she was adored, when her foster father died. The social worker advised them of some problems in a subsequent foster home, but assured them she was emotionally intact and would be fine in a good home. During the five years she lived with her adoptive family, Lisa's behavior deteriorated. She set a fire that almost burned down the house, stole things from classmates and family members, and fought repeatedly with her parents and older sister. Tension was so high that her sister's friends stopped coming over. Outpatient therapy proved useless. The situation climaxed when Lisa attempted to poison her father with Lysol. When she was subsequently institutionalized, Joan and Bob learned that the state had evaluated Lisa before the adoption, and that psychiatrists had recommended that she be institutionalized for long-term psychiatric care. Instead of providing that care, the state had placed Lisa for adoption, revealing

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Agencies should engage applicants in individual and group assessment and preparation that will educate the applicant to child and family issues in adoption. This process should stress that the needs of the child are paramount. During the assessment and preparation, adoptive applicants should have been informed about the usual reasons of why children are in need of adoption; that most infants and young children are born to single parents and that older children may have experienced abuse and neglect. (1.2)

Attitudes of adoptive parents about birth parents should have been considered during the assessment and preparation process and should be discussed in the postplacement period. Adoptive parents need help in understanding the circumstances of single parents: parents who were unwilling or unable to care responsibly for a child; and their own feelings about them. (5.5, 5.19)

In the case of older children, adoptive parents should be provided with information about the child's birth family situation that they will need both to help the child and to be aware of what the child knows about the birth parents.

Birth parents have a responsibility to provide the child welfare agency and/or the adoptive parents with information regarding any significant changes in their medical conditions resulting from hereditary conditions and any social information that may prove helpful to the adopted child.

CHILD WELFARE LEAGUE OF AMERICA, STANDARDS FOR ADOPTION SERVICE 37-39 (rev. ed. 1988).

Also in 1971, the American Academy of Pediatrics' Council on Child Health recognized an adoptee's need to learn his ancestry and encouraged pediatricians to make available information that they had acquired. Lampert, *supra* note 4, at 111.

104. Golden, *supra* note 3, at 16, 73. The names of the adoptive parents have been changed.

nothing of this evaluation to the adoptive parents.<sup>105</sup> By the time she was institutionalized five years later, it was too late. Lisa had not received the treatment she desperately needed. The family was torn apart. Bob and Joan filed a petition to revoke the adoption that was subsequently granted.<sup>106</sup> A few months later, Joan and Bob separated.<sup>107</sup> The stress of the failed adoption had left their marriage and family in ruins.

This case history is not unique. The policy of adoptive placement without full disclosure of psychiatric disorder has denied numerous adopted children effective therapy, at a staggering emotional and physical toll both to the children and to adoptive parents and siblings. Many of these children mutilate themselves or attempt suicide.<sup>108</sup> Many adoptive parents who were not given accurate information regarding their child's mental problems prior to placement report children setting fires, violently attacking siblings and adoptive parents, and engaging in other destructive behavior.<sup>109</sup> In addition to the threat of physical harm, the stress is psychologically injurious to siblings,<sup>110</sup> and can cause the adop-

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105. *Id.* at 82.

106. Prior to revocation, the Rhode Island Supreme Court ruled that the family court had inherent power to grant nullification of an adoption on grounds of fraudulent conduct by the public adoption agency. See *In re Lisa Diane G.*, 537 A.2d 131, 133 (R.I. 1988).

107. Golden, *supra* note 3, at 82.

108. *Id.* at 77. Tommy Colella, another child whose adoption revocation received national media coverage, attempted repeatedly to set fires, mutilate himself, and commit suicide by hanging prior to his institutionalization. Only later did his parents learn that the state had extensive files on his psychiatric disorder. Jack Friedman, *He's Not Our Son*, PEOPLE, July 11, 1988, at 38, 40, 41; Dianne Klein, *Adopted Boy's Hidden Past Led Family to Life of Terror*, L.A. TIMES, Jan. 4, 1988, § 2, at 1 (Orange Co. ed.); see also BARTH & BERRY, *supra* note 11, at 176 (describing eight-year-old child who practiced Satanic worship and sliced his penis to draw blood for ceremonies was placed with adoptive father who was unaware of this behavior at time of placement); Marshall Marvelli & Sylvia Marvelli, *Tom and Janice Colella*, PEOPLE, Aug. 1, 1988, at 6, 6 (letter to editor describing adopted daughter's self-abuse and preoccupation with fire).

109. See Belkin, *supra* note 2, at 1 (reporting that adopted child attempted to burn down his home and threatened younger brother with knife; parents subsequently learned state maintained large file on child describing abuse by birth father; attacks by other children also described); Golden, *supra* note 3, at 79, 82 (Jacob Clemens, in apparent suicide attempt, killed two younger brothers in fire; in another instance, "Debbie" attacked adoptive mother with knife); Bonnie Jacob, *Raising Cain*, NEW DOMINION, May/June 1989, at 33, 37; Klein, *supra* note 82, at 1 ("Monica" twice tried to suffocate baby sister; threatened mother three times with knife); Andrea Sachs, *When the Lullaby Ends*, TIME, June 4, 1990, at 82, 82 (adoptive parents learned after adoption that "violently disturbed" adoptee had been abused as a child; adoptee had tried to cut off adoptive cousin's arm and, on another occasion, to set fire to the cousin's room while he slept).

In Colorado an organization founded for parents of adoptive children who are violent and mentally ill gained 2,000 members in its first five months of operation. Belkin, *supra* note 2, at 1.

110. See account of Lisa G. in Golden, *supra* note 3, at 1; see also Jacob, *supra* note 109, at 35 (indicating that a previously well-adjusted sister began staying in her room behind closed

tive parents' marriage to crumble.<sup>111</sup> Although attempted adoption revocations are rare, they are increasing as adoptive parents feel defrauded, betrayed, and helpless to meet the emotional and financial demands of the child's disorder.<sup>112</sup> A more common response is the wave of "wrongful adoption" suits currently being waged against adoption agencies that failed to disclose their knowledge of the child's psychological or physical problems, genetic disorders, medical history, or other critical background information.<sup>113</sup>

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doors); Klein, *supra* note 82, at 16 (mother stated that other children lived in constant turmoil and fear because of "Monica's" behavior). The impact on siblings can be particularly harmful if biological siblings are adopted together and the adoption of one is later revoked, causing their separation. See generally Belkin, *supra* note 2, at 1 (describing how younger brother was terrorized by adoptee); Sharman Stein, *Spurned Adoptee Just Wants to See Brother*, CHI. TRIB., Apr. 5, 1990, § 1, at 1 (adopted siblings separated when adoptive parents surrendered one back to state and kept the other).

111. Golden, *supra* note 3, at 79 (quoting one adoptive mother, who now leads workshops for adoptive families: "A lot of people stay in the [adoptive] commitment after it doesn't work out. And to me, that's really unhealthy because it affects the rest of the family. I've seen so many marriages break up over it."); Jacob, *supra* note 109, at 35 (noting that stress caused the adoptive couple to fight continuously).

112. See *In re Adoption of Kay C.*, 228 Cal. App. 3d 741, 746, 757, 278 Cal. Rptr. 907, 909-10, 917 (1991) (upholding adoption revocation granted because adoptive parents had not been told prior to adoptive placement of child's serious mental illness and expert opinion advising against adoption); *M.L.B. v. Department of Health & Rehabilitative Servs.*, 599 So. 2d 87, 87-89 (Fla. Dist. Ct. App. 1990) (holding that one-year period in which to attack validity of adoption does not preclude motion to set aside adoption on grounds of alleged fraudulent concealment of child's psychiatric disorder); *In re Adoption of Haggerty*, No. CA-741, 1991 Ohio WL 115978, at \*5 (Ct. App. June 7, 1991) (rejecting as not timely a motion to vacate an adoption decree on grounds of fraudulent nondisclosure of child's behavior and emotional problems).

In a case reported by the *Los Angeles Times*, see Klein, *supra*, note 82, at 1, social workers failed to tell the adoptive parents of "Monica" about a long history of mental illness and drug abuse in her family. When the child was finally diagnosed as schizophrenic with a multiple-personality disorder, medical bills for her institutionalization forced the parents to seek termination of their parental rights. The court granted the parents the right to continue to visit with the child weekly and participate in her therapy; the court also allowed the child to visit the adoptive parents on weekends as her condition permitted. See also Belkin, *supra* note 2, at B8 (describing action to surrender custody of adopted child); Golden, *supra* note 3, at 82 (revocation action filed by parents never told of pre-placement psychological report that advised against adoption); Klein, *supra* note 108, at 1 (Tommy Colella); Marvelli & Marvelli, *supra* note 108, at 6 (attempted revocation of adoption of institutionalized child to obtain government assistance for staggering medical bills).

113. See, e.g., *Griffith v. Johnston*, 899 F.2d 1427, 1434 (5th Cir. 1990); *Collier v. Krane*, 763 F. Supp. 473, 474 (D. Colo. 1991); *Michael J. v. Los Angeles County Dep't of Adoptions*, 201 Cal. App. 3d 859, 863, 247 Cal. Rptr. 504, 507 (1988); *Richard P. v. Vista Del Mar Child Care Servs.*, 106 Cal. App. 3d 860, 863, 165 Cal. Rptr. 370, 373 (1980); *Wallerstein v. Hospital Corp. of Am.*, 573 So. 2d 9, 9 (Fla. Dist. Ct. App. 1990); *Krueger v. Leahy*, No. 89-L-18751 (Cook County Civ. Ct., Ill., filed Dec. 28, 1989); *M.H. v. Caritas Family Servs.*, 475 N.W.2d 94, 95 (Minn. Ct. App. 1991); *Foster v. Bass*, 575 So. 2d 967, 968 (Miss. 1990); *Allen v. Children's Servs.*, 58 Ohio App. 3d 41, 42, 567 N.E.2d 1346, 1348 (1990); *Wristen v. Jansen*, No. 86CV-10-6421 (Ct. of C.P., Franklin County, Ohio, filed Oct. 15, 1986); *Allen v. Allen*,

The most compelling argument for full disclosure of medical and social background information is that it can facilitate appropriate diagnosis and treatment for adopted children at an early stage. Children with psychiatric disorders often receive ineffective treatment for years, sometimes resulting in their being institutionalized, because adoptive parents and medical caregivers lack knowledge that could provide a clue to effective treatment.<sup>114</sup> By the time the severity of their condition is appreciated, it can be too late. Psychiatrists who work with psychopathic children, often referred to as "unattached children," say the chances of therapy being successful are greatly increased if the child is diagnosed when young.<sup>115</sup> For children over seven, the chances of success are only about fifty percent, and for children over eleven, the likelihood of recovery is even lower.<sup>116</sup> Information regarding substance abuse during pregnancy can facilitate diagnosis of fetal alcohol syndrome or other drug-related problems.<sup>117</sup> Knowledge of the occurrence of schizophrenia or

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214 Or. 664, 667, 330 P.2d 151, 154 (1958); *Gibbs v. Ernst*, No. 90003066 (Ct. of C.P., Bucks County, Pa., filed Apr. 4, 1990); *In re Lisa Diane G.*, 537 A.2d 131, 132 (R.I. 1988); *Martin v. Methodist Home*, No. 90-07815 (Dallas County Dist. Ct., Tex., filed July 2, 1990); *Phillips v. Texas Dep't of Human Servs.*, No. 90-07815 (Travis County. Dist. Ct., Tex., filed July 2, 1990); *Richards v. Texas Dep't of Human Servs.*, No. 476799 (Travis County Dist. Ct., Tex., filed Apr. 18, 1990); *Meracle v. Children's Servs. Soc'y*, 149 Wis. 2d 19, 20, 437 N.W.2d 532, 533 (1989); see also *Golden*, *supra* note 3, at 16 (describing wrongful adoption suit filed by Linda and John Murphy for \$4.1 million in Massachusetts); *Klein*, *supra* note 108, at 1 (wrongful adoption suit filed by Tom and Janice Colella); *One Million Sought in Adoption Suit*, CHI. TRIB., May 23, 1990, § 2 (Chicagoland), at 3 (wrongful adoption suit by Thomas Tinor and Elisabeth Novakovich against Bethany Christian Services in Illinois). Professor Neil Cogan of Southern Methodist University has filed 12 wrongful adoption actions, including three of the actions listed above. Telephone Interview with Neil Cogan, *supra* note 2.

114. See Dianne Klein, *An Adopted Boy—And Terror Begins*, L.A. TIMES, Jan. 4, 1988, § 1 (Home edition), at 3 (The adoptive mother of Tommy Colella, whose diagnosis of fetal alcohol syndrome with psychotic behavior was not shared with adoptive parents, observed, "[a]s awful as it was, we know that Tommy suffered more than we did. He was denied the treatment he needed. The system failed him."); *Klein*, *supra* note 82, at 1 ("Monica" endured years of inappropriate therapy before she was diagnosed as having multiple personality disorder and schizophrenia. She was ultimately institutionalized. Aware of her disturbed behavior, social workers for years withheld from the family an extensive history of schizophrenia in her biological family.); see also *Johnson*, *supra* note 16, at 36 (noting that knowledge of medical history allows families to anticipate health problems of adopted children); *Karwath*, *supra* note 3, at 12 (quoting adoptive mother of an institutionalized mentally retarded son who learned 12 years after adoption that both birth parents had been institutionalized for mental problems: "If we had had this information earlier maybe we could have been more aware of things to look for and gotten more expert help sooner.").

115. *MAGID & MCKELVEY*, *supra* note 102, at 149, 216.

116. *Id.* at 149. Psychologists are developing increasingly effective therapies for abused children, but proper implementation is aided by specific knowledge of the abuse. See John W. McInturf, *Preparing Special Needs Children for Adoption Through Use of a Life Book*, 65 CHILD WELFARE 373, 376, 378, 381 (1986).

117. See *Jacob*, *supra* note 109, at 36. One adoption agency withheld information collected from a foster mother that provided strong indications that the child suffered organic brain



manic-depression in other biological relatives can hasten diagnosis and appropriate drug therapy. One adopted child underwent years of therapy until she was diagnosed at age seventeen with bipolar disorder, a manic-depressive illness. Around the same time, her adoptive mother, after a long search, succeeded in obtaining information on the family history and discovered her daughter's biological father had been hospitalized for bipolar disorder. "Laura had so much pain and went undiagnosed for so long," her mother lamented. "She didn't just need family therapy, she needed lithium."<sup>118</sup>

Although the focus of the above discussion has been on psychiatric disorders, the need for information is equally compelling for adopted children at risk for physical disabilities and other genetic disorders. Geneticists,<sup>119</sup> adoptees, and adoptive parents<sup>120</sup> relate that adopted children often undergo painful, expensive, and sometimes hazardous diagnostic testing that could have been avoided if adequate medical history had been available. Some hereditary disorders, such as familial polyposis of the colon, can be life-threatening if not properly diagnosed and treated.<sup>121</sup> The ill effects of other hereditary disorders, such as phenylketonuria<sup>122</sup> or homocystinuria,<sup>123</sup> can be almost entirely avoided

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damage from fetal alcohol syndrome, a condition that ultimately caused his institutionalization. *Id.* at 48. "The cruel thing is that not knowing about John's condition has cost him so much time," said his adoptive father. "Time we spent on therapies that didn't work, time wasted when the doctors said, 'He's just a hyperactive, normal kid. He'll grow out of it.' Now it may be too late to help John or it may take 10 times longer than it would have if we'd started right in the first place." *Id.*

118. Deborah Franklin, *What a Child is Given*, N.Y. TIMES, Sept. 3, 1989, § 6, at 36, 41.

119. Ball & Omenn, *supra* note 4, at 277 (authors are geneticists who at time of publication were affiliated with the Federal Office of Science and Technology Policy); Omenn et al., *supra* note 85, at 162 (authors are geneticists and physicians who were affiliated with the Division of Medical Genetics, Depts. of Medicine and Pediatrics, University of Washington, Seattle).

120. See Whitehouse, *supra* note 3, at 19 (discovery by adult adoptee of history of fibrous breast lumps avoided repetition of painful treatment that might otherwise have been necessary); Franklin, *supra* note 118, at 40 (adoptee underwent painful tests to reach a diagnosis of juvenile chronic arthritis, a disease he later discovered was prevalent in his birth family).

121. Omenn et al., *supra* note 85, at 162. Familial polyposis causes polyps to form in late childhood, creating symptoms of chronic colitis. Carcinoma of the colon almost invariably develops if the disease is untreated. *STEDMAN'S MEDICAL DICTIONARY* 1238 (25th ed. 1990).

122. Phenylketonuria is a metabolic disease caused by an inherited enzyme defect, which causes brain damage resulting in severe mental retardation and, at times, seizures, cerebral palsy, and microcephaly. Early diagnosis and proper treatment, which consists of changes in the infant's diet, can prevent all symptoms of the disease. Screening is normally performed at birth. *STEDMAN'S MEDICAL DICTIONARY*, *supra* note 121, at 1185. In *Foster v. Bass*, 575 So. 2d 967 (Miss. 1990), an adoptive family received ambiguous information that led them and their pediatrician to conclude mistakenly the test had been performed. It had not, and the adopted child suffered permanent brain damage. *Id.* at 969 n.3.

123. Homocystinuria is a "congenital metabolic disorder resulting in an excess of the amino acid homocystine in the blood and urine," leading to "mental retardation and skeletal

if diagnosed early and treated properly. In other cases, knowledge of a disorder may warn families to watch for certain symptoms or avoid certain activities, including surgery or common medical treatment, that may create a higher risk for their child.<sup>124</sup> Identification, evaluation, and therapy for children with developmental delay is particularly critical to maximize their potential, because developmental impairment may increase if not treated early.<sup>125</sup>

Medical and social information continues to be relevant to proper diagnosis, treatment, and preventive measures throughout the adoptee's lifetime.<sup>126</sup> One adoptee, for example, reported that learning as an adult about a history of alcoholism on both sides of his biological family convinced him to be cautious about his own drinking pattern.<sup>127</sup> Adoptees also need accurate medical and genetic history to make informed choices about their own reproductive decisions.<sup>128</sup> Forewarning of a possible hereditary disorder may alert them to the need for prenatal genetic testing and counseling or amniocentesis. Access to their genetic history may also diminish the stress experienced by many adoptees in the past who, without access to medical history, suffered tremendous anxiety about the possibility of having children with severe deformities.<sup>129</sup>

Access to information regarding genetic heritage and background also enhances an adoptee's development of a personal sense of identity. The importance of this information has been increasingly recognized by

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defects if untreated." STEDMAN'S MEDICAL DICTIONARY, *supra* note 121, at 722. Children of incestuous relationships have increased risk for this and other recessive disorders. Lampert, *supra* note 4, at 114 & n.32.

124. For example, a genetic clinic contacted the adoptive parents of a child after her birth mother was diagnosed with a bleeding disorder known as von Willebrand Disease. The child had a 50% chance of contracting the disease. The clinic felt that the adoptive parents needed to be warned to take protective measures in situations where bleeding might occur and to perform certain tests before any elective surgery was undertaken. Omenn et al., *supra* note 85, at 161.

125. Susan Heighway, *Developmental Approach to Casefinding* (pt. 1), in GENETIC FAMILY HISTORY, *supra* note 1, at 93.

126. See SOROSKY et al., *supra* note 77, at 126-27; Ball & Omenn, *supra* note 4, at 277-78; Diane Plumridge et al., *ASHG Activities Relative to Education: Heredity and Adoption, A Survey of State Adoption Agencies*, 46 AM. J. HUMAN GENETICS 208, 212-13 (1990).

127. Adoptee Robert Morse observed, "Like a lot of kids in college, I used to go out and drink a lot on weekends. Now I know that's a danger for me, and I've stopped." Franklin, *supra* note 118, at 41. Robert Plomin, a developmental psychologist at Pennsylvania State University, has noted that it is just as important to tell an adoptee that the birth father was alcoholic as it is to share information on genetic diseases. He observes that if people know their genetic history and see symptoms of alcoholism developing, they are more likely to get help early. *Id.*

128. See Black, *supra* note 85, at 198; Omenn et al., *supra* note 85, at 162; Plumridge et al., *supra* note 126, at 209.

129. SOROSKY et al., *supra* note 77, at 124, 142, 144; Black, *supra* note 85, at 205.

professionals in the mental health and social services fields who work with adolescent and adult adoptees.<sup>130</sup> The term "genealogical bewilderment" has been used in psychological literature to describe symptoms associated with the identity conflict—caused by their lack of knowledge of the medical, social, and ethnic background of their biological parents and families—that many adoptees experience.<sup>131</sup>

Creation of an effective disclosure system that provides a mechanism for supplementation and transmission of information both before and after the adoption benefits not only the adoptee, but also facilitates medical treatment and reproductive planning for the adoptee's descendants and other biological relatives.<sup>132</sup>

Despite the importance of the benefits of full disclosure, however, the legitimate concerns of opponents must be addressed. One major concern is the adverse effect negative information could have on placement options for the child.<sup>133</sup> Professionals who place children with special needs for adoption now contend, however, that placing a child with a family prepared to meet the child's special needs must be a priority.<sup>134</sup>

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130. SOROSKY et al., *supra* note 77, at 132-42; Black, *supra* note 85, at 203-05; Robin M. Henig, *Body and Mind: Chosen and Given*, N.Y. TIMES, Sept. 11, 1988, § 6 (Magazine), at 70, 72. In *Mills v. Atlantic City Department of Vital Statistics*, 148 N.J. Super. 302, 372 A.2d 646 (Super. Ct. Ch. Div. 1977), the court summarized testimony by adoptees and psychologists emphasizing the importance of information about an adoptee's background to one's identity, self-image, and perceptions of reality. *Id.* at 309, 318-19, 372 A.2d at 650, 655. For similar stories, see *Backes v. Catholic Family & Community Services*, 210 N.J. Super. 186, 192-93, 509 A.2d 283, 286-87 (Super. Ct. Ch. Div. 1985), and Maureen Sweeney, *Between Sorrow and Happy Endings: A New Paradigm of Adoption*, 2 YALE J.L. & FEMINISM 329, 348 (1990).

131. *In re Assalone*, 512 A.2d 1383, 1388 & n.5 (R.I. 1986) (summarizing testimony of expert witness Dr. Brandon Qualls); CAPLAN, *supra* note 76, at 82; SOROSKY et al., *supra* note 77, at 113. The term was originally introduced by H.J. Sants, who described it as a state of confusion and uncertainty in adoptees who become obsessed with questions about their biological roots. H.J. Sants, *Genealogical Bewilderment in Children with Substitute Parents*, 87 BRIT. J. MED. PSYCHOL. 133, 133-41 (1964).

132. For a more detailed discussion of this topic, see *infra* text accompanying notes 239-45 (descendants), 251-59 (biological relatives), 454-62 (duty to update), and 477-85 (disclosure of updated information).

133. See *supra* notes 81-83 and accompanying text.

134. Diane Mahon, national director for AASK America Adoption Exchange, which specializes in placing special-needs children, states that the Exchange's policy is to make certain all health information it has is disclosed and explained. The more you tell a family about the child's needs and history, she stresses, the more likely the family is to take and deal with the child. Telephone Interview with Diane Mahon (Sept. 24, 1990). Similarly, Gloria Hochman, communications director for National Adoption Exchange, another national agency focusing on special-needs adoption, agrees that prospective adoptive parents must be given all available health information and that agencies must be truthful. Telephone Interview with Gloria Hochman (Sept. 18, 1990); see also NELSON, *supra* note 81, at 85-86 (reporting that study of special-needs adoption establishes importance of adequate information to adoptive parents); Black, *supra* note 85, at 195 (advising social workers that for children of incest, complete genetic information should be made available to potential adoptive parents because informed

Providing prospective adoptive parents with the most complete information available is essential to ensuring that the family is both emotionally and financially able to cope with the challenges such a child presents.<sup>135</sup> In fact, social scientists have discovered that failure to provide accurate information contributes significantly to adoption disruption,<sup>136</sup> which scars both the child and the adoptive family. In California alone, the state's records attribute sixty-nine annulled adoptions between 1983 and 1987 to fraudulent misrepresentation of a child by a county agency.<sup>137</sup> Even if the adoption does not disrupt, an adoptive family can better cope with potential difficulties if it is prepared to meet them.<sup>138</sup> Gloria Hochman, communications director for the National Adoption Exchange, observed that "it makes no sense to place a child with a family who won't be able to deal with that child. . . . This is not a poker game. These kids need families with the ability to nurture" them.<sup>139</sup>

Moreover, while some families will choose not to adopt a child with special needs, professionals who specialize in placing such children indicate that many adoptive families are willing to undertake this special challenge.<sup>140</sup> There are waiting lists of families seeking to adopt spina

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decisionmaking remains an absolute necessity). See generally Barbara Biesecker, *Genetic Counseling: A Case Study*, in GENETIC FAMILY HISTORY, *supra* note 1, at 79, 87 (noting that in genetic counseling, truthfulness with families is mandatory: "The sooner they learn the truth, the sooner they will find the strength to deal with the information.").

135. NELSON, *supra* note 81, at 48-49, 85-86. "Arguably, the parents' own informed opinion about the suitability of a placement is one of the best predictors of outcome. The most effective preparation, then, does not merely educate parents; it enables them to take charge of placement decisions." *Id.* See generally John R. Maley, Note, *Wrongful Adoption: Monetary Damages is a Superior Remedy to Annulment for Adoptive Parents Victimized By Adoption Fraud*, 20 IND. L. REV. 709, 725 (1987) (asserting that if fully informed, adoptive parents are better "able to deal with the emotional hardships which might result when the risks become reality"); Klein, *supra* note 82, at 1 (arguing that incomplete disclosure may cause parents to be ill-prepared to deal with physical or mental illness; most professional guidelines stress the importance of complete disclosure).

136. BARTH & BERRY, *supra* note 11, at 169; MAGID & MCKELVEY, *supra* note 102, at 296-97; NELSON, *supra* note 81, at 84 (providing insufficient or inaccurate information about child contributed to most disruptions occurring in group of special-needs adoptions studied).

137. Klein, *supra* note 82, at 32.

138. BARTH & BERRY, *supra* note 11, at 175-76.

139. Telephone Interview with Gloria Hochman, *supra* note 134.

140. Gloria Hochman, communications director of National Adoption Exchange, commented that there is no child for whom she would say that the Exchange could not find a family. At the time of this telephone interview, it had recently placed very quickly a blind, mentally retarded child who had difficulty walking. The Exchange has even found families for children in essentially vegetative states. She conceded that while it does find homes for most children, the Exchange has not found homes for every one. Some grow too old while waiting. *Id.*; see Telephone Interview with Diane Mahon, *supra* note 134; see also Black, *supra* note 85, at 195 (arguing that many parents may be willing to adopt a newborn in the face of a higher risk of genetic disorders due to incest); Lampport, *supra* note 4, at 115 (reporting that prospec-

bifida children<sup>141</sup> and Down's Syndrome<sup>142</sup> children at all functioning levels. Diane Mahon, national director of AASK America Adoption Exchange, reports that the Exchange has no trouble finding homes for children with all types of special needs, whether the disabilities are physical, mental, or emotional.<sup>143</sup> Its primary problem is "getting the kids out of the system"—confronting the bureaucratic morass that accompanies adoptions, particularly those that are inter-state.<sup>144</sup> Psychologists and adoption specialists are also beginning to recognize that adoption may not be the most appropriate way to meet some children's needs at a given time.<sup>145</sup> For the vast majority of special-needs children for whom adoption is appropriate, however, full disclosure will not prevent them from finding an adoptive home, and should instead enhance their chances for a successful placement.

The concern that disclosure of negative information will cause stigmatization cannot be dismissed lightly.<sup>146</sup> This issue, however, is better addressed by providing education and counseling to adoptive parents and

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tive adoptive parents advised of significant risk of schizophrenia and chose to adopt child anyway); *San Francisco, AIDS POL'Y & L.*, July 11, 1990, at 7, 7 (noting that program in Yonkers, N.Y., placing HIV-positive children abandoned by parents reports 52% of foster families were willing to adopt HIV children placed with them).

141. Telephone Interview with Judy Gustafson, coordinator, Spina Bifida Adoption Referral Program (Sept. 18, 1990).

142. Telephone Interview with Janet Marchese, director and founder, Down's Syndrome Adoption Exchange (Sept. 18, 1990).

143. Telephone Interview with Diane Mahon, *supra* note 134. Mahon stated that the Exchange normally is able to find homes for all its children. She observed that her most difficult challenge was placing groups of siblings. She also emphasized that all of her families must successfully complete home studies to ensure that they are appropriate adoptive homes. *Id.*

144. *Id.* Mahon related that if she finds a family willing to adopt a special-needs child residing in another state, the receiving state will often be reluctant to facilitate the adoption due to concern over public services and expenditures the child might require. Janet Marchese of the Down's Syndrome Adoption Exchange also commented on problems with interstate transfer and bureaucratic delays. Telephone Interview with Janet Marchese, *supra* note 142.

145. Jeffrey Rosenberg, director of public policy for the National Committee for Adoption and a strong advocate of agency adoption, has observed that some children are not adoptable—a lesson, he cautions, that adoption agencies sometimes forget. "Some children aren't meant for some parents, some parents aren't meant for some children, and some children probably aren't meant to be adopted." Jeffrey Rosenberg, *Some Kids Can't Be Adopted*, WASH. POST, Jan. 12, 1988, at Z4 (letter to the editor). Mr. Rosenberg's letter was written in response to a story about the adoption of Tommy Colella, a severely disturbed child whose adoption was ultimately revoked. *See supra* note 108. In another article Rosenberg was quoted as saying, "There are some kids that have been so abused that they'll never attach or bond. It's so scary that they'll do whatever they can to prevent it." Golden, *supra* note 3, at 18.

Public agencies have placed children for adoption after psychiatric evaluation recommended long-term residential psychiatric care. *See id.* (preplacement psychological reports advised against adoption); *supra* text accompanying notes 104-05.

146. *See supra* notes 84-90 and accompanying text.

children than by denying access to information.<sup>147</sup> For example, parents and adoptees advised of an increased risk of schizophrenia or alcoholism must be made aware that the overwhelming majority of children born to parents with those problems do *not* develop the disorder.<sup>148</sup> Their attention should be directed to the fact that environment remains an important component of human development.<sup>149</sup> Experts stress the need for preplacement counseling to assist families who adopt children known to be at risk for physical or mental problems.<sup>150</sup> Also critical to overcoming adverse consequences to adoptive family relationships is a follow-up support network that provides contact with other adoptive families and trained professionals who can offer information and counseling.<sup>151</sup> Moreover, while the potential effects of stigmatization on the adoptive family's interaction and the child's sense of identity are serious concerns, the psychological effects of nondisclosure on both adoptive parents and children, as described above,<sup>152</sup> can be equally troubling. Even when a physical or mental disorder does not immediately appear, both adoptive parents and children suffer anxiety over the unknown.<sup>153</sup> One adoptive mother and social worker, who worked in the field for twenty years, countered the stigmatization concern: " 'Everyone I have ever worked with has said it is always better to know the history than to not know. Because, believe me, it's the parents who don't know who imagine the worst if they have a child who seems troubled.' " <sup>154</sup>

While adverse genetic information could create insurance problems for some families,<sup>155</sup> nondisclosure has been financially devastating for many who adopted without awareness of their child's medical needs. The cost of residential psychiatric care can reach as high as \$15,000 per

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147. Black, *supra* note 85, at 198-99; Omenn et al., *supra* note 85, at 161-63.

148. Black, *supra* note 85, at 202.

149. See *id.* at 158; Franklin, *supra* note 118, at 49 (citing Robert Plomin, a developmental psychologist at Pennsylvania State University, who cautions that "the current infatuation with genetic influences has obscured the very real importance of environment in human development").

150. BARTH & BERRY, *supra* note 11, at 169-70.

151. ADOPTION LAW AND PRACTICE, *supra* note 76, § 9.04[4], at 9-27 to -28; Black, *supra* note 85, at 199; Golden, *supra* note 3, at 76. AASK America Adoption Exchange, which specializes in the placement of special-needs children, offers postadoption services and support groups throughout the lifetime of the adopted child. Telephone Interview with Diane Mahon, *supra* note 134.

152. See *supra* notes 104-12 and accompanying text.

153. SOROSKY et al., *supra* note 77, at 85, 185; Black, *supra* note 85, at 205.

154. Franklin, *supra* note 118, at 41 (quoting Marietta Spencer, social worker for the Children's Home Society of Minnesota in St. Paul).

155. See *supra* note 91 and accompanying text.

month.<sup>156</sup> Some adoptive parents have been forced to seek revocation to force the state to assume these costs.<sup>157</sup>

Sometimes these financial burdens can be lessened if prospective adoptive parents are given the necessary medical information to qualify for federal and state adoption assistance benefits.<sup>158</sup> These benefits are available to families who adopt special-needs children and meet certain eligibility criteria.<sup>159</sup> They can include medical assistance under Medicaid and various state programs,<sup>160</sup> as well as such social services as respite care, specialized day care, counseling, and in-home support services.<sup>161</sup> To be eligible for adoption assistance, however, it must be established that the child had special needs at the time of the adoption.<sup>162</sup> Adoptive parents cannot apply for federal adoption assistance after the

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156. Johnson, *supra* note 16, at 36; *see also* Belkin, *supra* note 2, at B8 (discussing costs of care).

157. Klein, *supra* note 82, at 33-34 (noting adoptive parents forced to sell family business and ultimately seek revocation to pay mounting bills); Marvelli & Marvelli, *supra* note 108, at 6 (attempted revocation to obtain governmental assistance).

158. Since passage of the Adoption Assistance and Child Welfare Act of 1980, the federal government has reimbursed states for adoption assistance benefits they give to families that adopt eligible children with special needs. In addition, each state has its own state-funded adoption assistance program. The federal program was created to complement rather than replace the state programs, which often cover children who do not meet the requirements for federal assistance and to provide benefits not available in the federal program. ADOPTION LAW AND PRACTICE, *supra* note 76, § 9.01[2].

159. To be eligible for federal benefits, a child must be determined by a state to be one with special needs, 42 U.S.C. § 673(c) (Supp. 1991), and within the financial and categorical criteria of either the Aid to Families with Dependent Children (AFDC) program or the Supplemental Security Income (SSI) program. *Id.* § 673(b). To classify a child as one with special needs, a state must find that the child cannot or should not be returned to the child's parents; that there is a specific factor which makes it reasonable to conclude that the child cannot be placed for adoption without assistance; and that reasonable efforts have been made to place the child without assistance, unless such efforts would not be in the best interest of the child—*i.e.*, the child has become attached to the prospective adoptive parents. *Id.* § 673(c); ADOPTION LAW AND PRACTICE, *supra* note 76, §§ 9.03, 9.03[1]. Factors that may make a child eligible include physical, mental, or emotional handicaps. *Id.* § 9.03[1][b].

State eligibility requirements vary, although they also tend to limit adoption assistance to children who, because of special needs, are more difficult to place. *Id.* § 9.03.

160. Federal Medicaid benefits include inpatient hospital services (except institutions for a mental disease or tuberculosis), outpatient hospital services, laboratory and X-ray services, early periodic screening and diagnosis for physical or mental disorders, and some types of medical treatment. 42 U.S.C. § 1396d(a)(1)-(2), (4)(B), (5) (Supp. 1991). Some states may choose to include in their Medicaid programs home health care services, private-duty nursing services, physical therapy, dental care, prescription drugs, inpatient psychiatric services, or other diagnostic, preventative, or rehabilitative services. *Id.* § 1396d(a); ADOPTION LAW AND PRACTICE, *supra* note 76, § 9.04[3], at 9-25.

161. ADOPTION LAW AND PRACTICE, *supra* note 76, § 9.04[4], at 9-27 to 9-28.

162. To be eligible for federal adoption assistance, the child must meet eligibility criteria at the time the adoption agreement is made. 42 U.S.C. § 673(a)(2)(A)(i). Some states will allow adoptive parents to apply for state adoption assistance benefits based upon pre-existing condi-

adoption has been completed, unless they can show they were not provided with all of the relevant information about the child's condition at the time they requested assistance.<sup>163</sup> Full disclosure is thus necessary to alert prospective adoptive parents to their potential eligibility and the need to apply for these benefits prior to finalization, and to ensure that eligible adoptive families receive these benefits for the full period they are entitled to them.<sup>164</sup>

The argument that medical and social history should not be disclosed to prospective adoptive parents or adoptees to protect the privacy of birth parents<sup>165</sup> is overbroad. Certainly, in defining the scope of collection efforts and identifying those to whom disclosure is made, state legislatures must consider the privacy interests of all concerned parties. This problem is discussed in greater detail in Part III.<sup>166</sup> But no reasonable expectation of privacy should foreclose absolutely the disclosure of medical and social background information to adoptive parents and adoptees. In most instances, the information can be collected in a non-threatening, cooperative manner and released with all identifying information redacted. Any benefit this history might provide to an adoptee searching for birth parents would be slight.

In addition, many birth parents would welcome the release of background information to adoptive parents. Currently, much of this information is voluntarily obtained from birth parents as part of the adoption process. In a sociological study of birth parents in the mid-1970s, ninety-five percent of the respondents indicated an interest in updating information about themselves in the agency records.<sup>167</sup> One scholar, herself a

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tions if the adoptive parents had no knowledge of these conditions at the time of the adoption. ADOPTION LAW AND PRACTICE, *supra* note 76, § 9.04[6][a].

163. 42 U.S.C. § 673(a)(5); ADOPTION LAW AND PRACTICE, *supra* note 76, § 9.04[6][a] (Supp. 1991) (citing Eligibility for Title IV-E Adoption Assistance, U.S. Department of Health and Human Services, Human Development Service, Policy Interpretation Question ACYF-P1Q-88-06 (Dec. 2, 1988)).

164. Federal law allows states and adoptive parents to negotiate an adoption assistance agreement that will take effect upon placement, so that the family will be eligible for benefits without having to wait for issuance of an interlocutory or final decree of adoption. ADOPTION LAW AND PRACTICE, *supra* note 76, § 9.04[6][a].

165. See *supra* text accompanying notes 92-93.

166. See, e.g., *infra* text accompanying notes 239-45.

167. SOROSKY et al., *supra* note 77, at 53. It should be noted, however, that the study could not be conducted upon a "random sample" of birth parents. The group interviewed was among hundreds who responded by letter to advertisements and media coverage of the study. Thirty-eight birth parents were interviewed, of whom 36 were birth mothers. *Id.* at 50-51.

In this study, 82% of the birth parents stated that they would be interested in a reunion with their child if the adoptee desired it. On the other hand, 53% favored opening sealed records to adult adoptees. *Id.* at 53-54.

Other social workers in the adoption field also have reported that the response they re-



birth mother, argues that secrecy has been overemphasized in traditional adoption procedure due to society's prejudices surrounding illegitimacy, a concept rooted in sexism and one that does not bear the same importance in a birth mother's decisionmaking.<sup>168</sup> Her assessment is supported by the absence of any significant decrease in adoptions in states that allow adult adoptees access to records to obtain their birth parents' identity.<sup>169</sup>

Although some birth parents may not approve the release of any background information, particularly if the information is perceived as negative or embarrassing, their right to privacy must be balanced with the needs of the adoptee.<sup>170</sup> Statutorily authorized disclosure of medical and social history to adoptive parents, adoptees, and descendants serves an important public interest—it contributes to the physical and mental health of adoptees and their descendants. Courts traditionally have approved disclosure of private information to protect a third party from harm.<sup>171</sup> When sufficient procedures exist to guard against unwarranted disclosure, these interests should take priority.

Finally, some critics of disclosure suggest that prospective adoptive parents who desire information on the medical and social history of a child, and who might allow their decision to adopt a particular child to be influenced by that information, are unworthy of parenthood.<sup>172</sup> They speak derisively of the search for the "perfect baby." Given today's demographics, however, the notion that couples wishing to adopt can somehow use the process to seek a "perfect baby" is patently absurd. The National Committee for Adoption estimates that there are at least twenty prospective adoptive couples per adoptable child.<sup>173</sup> Such critics would probably not suggest that couples who undergo prenatal genetic counseling or amniocentesis are unworthy of parenthood. It is unfair to expect that a couple will feel a commitment to parent a particular child whom they have never met and who simply has been described to them,

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ceived from birth parents to opening adoption records was overwhelmingly positive. Ryan, *supra* note 4, at 16.

168. Sweeney, *supra* note 130, at 355-57. The role of the "stigma of illegitimacy" in preserving secrecy is illustrated in *Mills v. Atlantic City Department of Vital Statistics*, 148 N.J. Super. 302, 307, 372 A.2d 646, 649 (Super. Ct. Ch. Div. 1977).

169. Sweeney, *supra* note 130, at 359; *see also* Prager & Rothstein, *supra* note 43, at 150 (reporting that adoption consultant for state allowing adult adoptees to learn birth parents' identity has found no problems resulting from law).

170. *See supra* notes 70-75 and accompanying text.

171. Ball & Omenn, *supra* note 4, at 273; Gauthier, *supra* note 60, at S:352.

172. *Cf. supra* notes 99-101 and accompanying text (noting that couples with such information might seek the "perfect child").

173. ADOPTION FACTBOOK, *supra* note 86, at 6.

despite all obstacles, in the same way parents might immediately after birth. Adoptive parenting is different from biological parenting in some respects.<sup>174</sup> Bonding comes through development of a relationship, not from biological ties. Many adoptive families willingly accept the challenges of adopting a child with special needs.<sup>175</sup> It is in everyone's best interests, however, for prospective adoptive parents to make informed decisions about the nature of the challenges with which they can cope.<sup>176</sup> Starting out with realistic expectations increases the chances that the relationship will be rewarding both for the child and for the adoptive parents.

In sum, while one cannot altogether dismiss concerns about disclosure of social and medical history, the benefits of disclosure and the tragic consequences of nondisclosure outweigh them. For this reason most states have moved during the past twelve years to adopt legislation permitting some disclosure of medical and social history as part of the adoption process.

### III. REVIEW OF CURRENT LEGISLATION AND THE NEED FOR FURTHER REFORM

While the attempt by many states to permit fuller disclosure of health-related information in adoptions has been praiseworthy, the efforts of most remain incomplete. This section examines deficiencies in the existing statutory regulation of this field and offers proposals to maximize the transmission of medical and social history to everyone with a legitimate need, while giving due consideration to the privacy interests of all concerned.

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174. One adoption social worker observed:

[A]doptive parents are entitled to know more genetic information than birth parents. We must recognize adoptive parenting differs from biological parenting. If adoptive parents are going to be realistic parents, they must recognize the differences too. The primary difference is that the child does not come to the family through their own means or biological processes, but rather through another family. Adoptive parents should have as much information available as possible. It is far better for them to decide they can't parent a child before the child is placed, having been given all the information, than making that decision when the child is already in the home.

Fost, *supra* note 84, at 55.

175. See *supra* notes 140-43 and accompanying text.

176. One expert in special-needs adoptive placement emphasized that an agency must work to get a good match between the child's characteristics and the family. Some families can tolerate one kind of behavior, such as setting fires, but not another, such as chronic depression and sulking. Telephone Interview with Gloria Hochman, *supra* note 134.

### A. *Mandatory Versus Discretionary Disclosure*

The vast majority of states mandate that certain background information "shall" be provided to adoptive parents.<sup>177</sup> Several states, however, have chosen to leave the decision regarding disclosure of information to the discretion of the state or a private adoption agency,<sup>178</sup> and a few leave the decision to the discretion of the court by requiring a court order for the release of information.<sup>179</sup> South Carolina, for example, allows the release of nonidentifying health information to adoptive parents, biological parents, or adoptees "in the sole discretion of the chief executive officer of the agency" if he perceives release would "serve the best interests of the persons concerned."<sup>180</sup>

Allowing a state social services department or private adoption agency sole discretion to determine what, if any, background information will be released fosters continuation of the same practices that generate disrupted adoptions, untreated or misdiagnosed children, and myriad

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177. See ALA. CODE § 26-10A-31 (Supp. 1991); ALASKA STAT. § 18.50.510 (1991); ARIZ. REV. STAT. ANN. § 8-129 (1989); ARK. CODE ANN. § 9-9-505 (Michie 1991); CAL. CIV. CODE § 224.76 (West Supp. 1991); COLO. REV. STAT. § 19-5-207 (Supp. 1991); CONN. GEN. STAT. ANN. § 45a-746 (West Supp. 1991); FLA. STAT. ANN. § 63.162 (West Supp. 1991); GA. CODE ANN. § 19-8-23 (Michie 1991); HAW. REV. STAT. § 578.14.5 (Supp. 1990); ILL. ANN. STAT. ch. 40, para. 1522.4 (Smith-Hurd Supp. 1991); IND. CODE ANN. § 31-3-4-14 (Burns 1987 & Supp. 1991); IOWA CODE ANN. § 600.8 (West Supp. 1991); KAN. STAT. ANN. § 59-2130 (Supp. 1990); KY. REV. STAT. ANN. § 199.520 (Michie/Bobbs-Merrill 1991); LA. REV. STAT. ANN. § 9:422.13 (West 1991); MD. FAM. LAW CODE ANN. § 5-329.1 (Supp. 1991); MASS. ANN. LAWS ch. 210, § 5A (Law. Co-op 1981); MICH. COMP. LAWS ANN. § 710.68 (West Supp. 1991); MO. ANN. STAT. § 453.121 (Vernon Supp. 1991); MONT. CODE ANN. § 40-8-122 (1991); NEB. REV. STAT. § 43-107 (Supp. 1990); N.H. REV. STAT. ANN. § 170-B:19 (1990 & Supp. 1991); N.J. STAT. ANN. § 9:3-41.1 (West Supp. 1991); N.Y. SOC. SERV. LAW § 373-a (McKinney Supp. 1991); N.C. GEN. STAT. § 48-25 (1991); N.D. CENT. CODE § 14-15-16 (1991); OHIO REV. CODE ANN. § 3107.12 (Anderson 1989); OR. REV. STAT. § 109.342 (1991); PA. STAT. ANN. tit. 23, § 2909 (1991); S.D. CODIFIED LAWS ANN. § 25-6-15.2 (Supp. 1991); TEX. FAM. CODE ANN. § 16.032 (West Supp. 1991); UTAH CODE ANN. § 78-30-17 (1987); VT. STAT. ANN. tit. 15, § 461 (1989 & Supp. 1991); VA. CODE ANN. § 63.1-223 (Michie 1991); WASH. REV. CODE ANN. § 26.33.350 (West Supp. 1991); WIS. STAT. ANN. § 48.432 (West Supp. 1991); see also UNIF. ADOPTION ACT § 16 (Tentative Draft Aug. 1991) (requiring individual or agency placing a child for adoption to provide prospective adoptive parents with comprehensive medical and social history of child and child's biological family).

178. See DEL. CODE ANN. tit. 13, § 924 (Supp. 1990); N.M. STAT. ANN. § 40-7-53 (Michie 1989); OKLA. STAT. ANN. tit. 10, § 57 (West Supp. 1992); S.C. CODE ANN. § 20-7-1780 (Law. Co-op. Supp. 1990); W. VA. CODE § 48-4-10 (1986 & Supp. 1991).

179. See D.C. CODE ANN. § 16-311 (1989); ME. REV. STAT. ANN. tit. 19, § 534 (West Supp. 1990); NEV. REV. STAT. § 127.140 (1985); R.I. GEN. LAWS § 8-10-3 (Supp. 1991); see also DEL. CODE ANN. tit. 13, § 925 (Supp. 1990) (giving public or private adoption agencies discretion to release nonidentifying information; otherwise requiring court order for release of health-related information).

180. S.C. CODE ANN. § 20-7-1780 (Law. Co-op. Supp. 1990).

wrongful adoption suits.<sup>181</sup> While many agencies have determined that full disclosure is the best policy and that professional guidelines require it,<sup>182</sup> the cost and effort required to obtain complete data,<sup>183</sup> the financial pressure to place special-needs children quickly in order to conserve public or agency resources,<sup>184</sup> and the bureaucratic pressure to generate placement statistics<sup>185</sup> all may influence social workers to release incomplete information. Specialists in the adoption field concede the effect of these factors. Reuben Pannor, one of the nation's leading adoption specialists and a former director of a private Los Angeles agency, Vista del Mar, has been openly critical:

"The goal is to get them off the rolls, find permanent homes, adoptive homes, which means that the state and county no longer have financial responsibility. . . . [But] there has been an over-zealousness about placing these 'special needs' children. Many have been placed without proper preparation, background testing, without information about what problems the child has, or about recessive problems that may show up later."<sup>186</sup>

Jeffrey Rosenberg, director of public policy for the National Committee

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181. For a discussion of the repercussions of such practices, see *supra* notes 104-29 and accompanying text.

182. See *supra* notes 102-03 and accompanying text.

183. See Klein, *supra* note 82, at 31. Despite professional guidelines that stress the importance of complete disclosure, social workers admit that at times, "because information may be difficult, expensive or time-consuming to obtain, it is simply left out." *Id.* An adoption supervisor with the Los Angeles Department of Children's Services, one of the nation's largest adoption agencies, states: "[I]t is extremely difficult to do. . . . Those pieces [of information] are missing. We know that. We have to cut corners in efforts to gather all available information about a child's background." *Id.*

184. See *id.* at 33 ("[P]ublic adoption officials describe a system swamped with children who need to be placed, a situation that social workers say has created pressure to place more and more children at a faster rate.").

The shortage of staff necessary to carry out the appropriate investigation, testing, and evaluation can result in children waiting years for adoption. Because social workers know this delay may exacerbate a child's emotional problems, the shortage of agency resources thus contributes to hasty placements. *Id.*

185. *Id.* ("What has become important are numbers. Placement numbers in adoptions become the ranking of how efficient a worker is."). The importance placed on statistics often results from the relationship between the number of placements and state funding. Frank Guzevich, regional manager at Riverside County's Department of Public Social Services in California, acknowledged the necessity of generating statistics to justify retention of staff. *Id.*

Private adoption agencies are not immune from these pressures. Although some of them are funded in part by donations, private agencies recover most of their costs through fees paid by adoptive parents. Thus, placements are necessary for their survival. Sharon F. Gustafson, *Regulating Adoption Intermediaries: Ensuring that the Solutions Are No Worse than the Problem*, 3 GEO. J. LEGAL ETHICS 837, 848 (1990).

186. Klein, *supra* note 82, at 33 (quoting Reuben Pannor).

for Adoption,<sup>187</sup> acknowledged that "[t]here is a great deal of pressure to place these kids, 'move 'em, move 'em, move 'em' . . . [S]o what happens is this wrongful adoption stuff. We hope not too much, but we don't know.'"<sup>188</sup> One adoption social worker reported to the media that the director of her agency told her to "[p]lace them as rapidly as you can. If we have to disrupt [a placement], fine. We can disrupt it. That makes for more placements and that means better statistics.'"<sup>189</sup>

When the choice is left to an agency or social worker, the extent of nondisclosure is significant.<sup>190</sup> For example, a study of older child adoptions and adoption disruptions conducted at the University of California at Berkeley in the early 1980s involving interviews with both adoptive families and social workers revealed that more than half of the families interviewed had not been told prior to placement that their adoptee had been sexually abused.<sup>191</sup> The study also revealed that almost one-third of the families whose adoptee had been physically abused were not informed of this abuse.<sup>192</sup> Twenty-eight percent of the families had not been told of a physical or medical disability prior to placement, one-fourth had not been told of a developmental disability, and over one-third had not been told of a learning disability, or emotional or behavioral problems.<sup>193</sup> In only 23% of these cases did the social worker claim that the reason for nondisclosure was that the worker did not know of

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187. The National Committee for Adoption is an advocacy organization that represents the interests of public and private adoption agencies and promotes agency adoption. ADOPTION FACTBOOK, *supra* note 86, at 10.

188. Klein, *supra* note 82, at 34 (quoting Jeffrey Rosenberg).

189. *Id.* at 33 (quoting Charleen Morrow, former social worker in Riverside County, California).

190. *Id.* at 1. Adoption experts "contend that vital information on adopted children, ranging from past abuse to important medical and psychological information about birth parents, is frequently withheld from adoptive parents, despite professional guidelines—and in some cases laws—calling for full disclosure." *Id.*; see also Jacob, *supra* note 109, at 48 (reporting that agency failed to provide adoptive parents with information from foster mother of tremors, convulsions, spasms, and rages that led her to conclude the child was a drug or alcohol baby).

191. BARTH & BERRY, *supra* note 11, at 78-87. The overall sample of cases in which the social worker or parent(s) were interviewed was 120. In 69 cases both the parent(s) and the social worker were interviewed, in 22 cases just the parent(s) were interviewed, and in 29 cases only the social worker was interviewed. Of the 120 interviews with a social worker or parent(s), in 57 an adoption disruption had occurred; 63 were stable families. Of the 69 cases in which both the parent(s) and the social worker were interviewed, disruption had occurred in 18. Of the 22 cases in which only parent(s) were interviewed, 13 had disrupted adoptions, and in 26 of the 29 cases in which a social worker only was interviewed, disruption had occurred. *Id.* at 80 tbl. 4.1.

192. *Id.* at 108. In all of these cases, interviews with a parent or parents had taken place. *Id.*

193. *Id.* at 109 tbl. 6.3.

the condition.<sup>194</sup> A study sponsored by the Child Welfare League of America of families who adopted special-needs children reached similar conclusions. Of the 102 families in which the adoptive parents had not been foster parents to the child they adopted, 52% were dissatisfied with the information they had been given about the child and 36% responded that the information had been partly or completely inaccurate.<sup>195</sup> Although the parents most often attributed the lack of information to organizational factors such as worker overload, seven suspected information was deliberately withheld and seventeen felt the social worker had misled them.<sup>196</sup> Corroborating these findings are reports from adoptive parents of severely disturbed children that they were pressured to agree to immediate placement with little or no information—in one case without even seeing the child.<sup>197</sup>

Requiring a court order for disclosure is also problematic. Obtaining a court order requires parents to incur further legal fees to obtain medical information, creating a significant deterrent to seeking health information—until a crisis occurs.<sup>198</sup> Broad standards leave the decision totally dependent on the discretion and idiosyncracies of the judge to whom application is made.<sup>199</sup> Thus access to health information may

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194. *Id.*

195. NELSON, *supra* note 81, at 34-35.

196. *Id.* at 35.

197. Tom and Janice Colella, who recently settled a wrongful adoption case with the Department of Social Services of Orange County, California, report that they were called by a social worker who told them that a seven-year-old boy was available for adoption and asked them to take the child that day, sight unseen. Although they insisted on meeting the child first, they were never told of his long record of sociopathic behavior. Friedman, *supra* note 108, at 40. The Walters, adoptive parents of two boys with severe psychological and emotional problems, reported that after one meeting with a pair of five- and eight-year-old brothers, the social worker wanted an answer: yes or no? No information on their history of abuse or neurological problems was provided. Klein, *supra* note 82, at 34.

One journalist reporting on the overrepresentation of adopted adolescents in mental-health treatment facilities observed that "[b]y placing these disturbed children with adoptive parents without providing enough support, society delayed their access to treatment and perhaps lost the chance to cure them. . . . [T]he government temporarily avoided picking up the tab, only to pay a bigger bill later." Golden, *supra* note 3, at 80.

198. An adoptive parent may well be unlikely to pay the expensive legal fees necessary to initiate a court proceeding to obtain information unless the parent feels the need is critical and the court is likely to find "good cause." Information on such things as allergies or genetic conditions that have not caused dramatic symptoms are likely to remain undisclosed.

199. In Tennessee a judge or chancellor may "open the record, if, in the opinion of the judge or chancellor, it is in the best interest of the child or the public to have such information disclosed." TENN. CODE. ANN. § 36-1-131 (1991). A District of Columbia statute provides that adoption files shall be inspected only upon order of the court, and then only "when the court is satisfied that the welfare of the child will thereby be promoted or protected." D.C. CODE ANN. § 16-311 (1989).

An illustration of the wide disparity created by broad standards for judicial discretion in

vary widely among adoptive parents in the same state.

If the goals of disclosure are to be effectively served, the release of nonidentifying health-related information to adoptive parents and to others, as described below,<sup>200</sup> should be mandatory and not left subject to the real or imagined pressures felt by state or private agencies, or to the discretion of a particular judge.

## B. *Applicability to All Adoptions*

### 1. Independent Adoptions

The mandatory disclosure laws currently in force do not uniformly apply to all adoptions occurring within the state. Perhaps the most striking example of this is Oklahoma's recently amended disclosure statute, which allows state or private adoption agencies to release the medical history of the child and the child's natural parents and grandparents to prospective adoptive parents, but fails to grant the same authority to attorneys who handle independent adoptions,<sup>201</sup> a significant percentage of the state's adoptions.<sup>202</sup> The disclosure statutes of several other states that permit independent adoptions also refer only to state and private agencies.<sup>203</sup> Clearly, access to medical information is equally important

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this area can be seen in courts' interpretation of "good cause" for opening adoption records for identifying information. See Gloria L. Kelly, Note, *Getting to Know You: Disclosure of Information Contained in Sealed Adoption Records Under Connecticut Public Act 87-555*, 5 CONN. PROB. L.J. 81, 86-91 (1989). One New Jersey court held that a psychological need-to-know may constitute good cause to receive identifying information, and that requests for medical, hereditary, or ethnic background information should be granted unless there is a showing of compelling reasons to withhold the information. See *Mills v. Atlantic City Dep't of Vital Statistics*, 148 N.J. Super. 302, 318-22, 372 A.2d 646, 655-56 (Super. Ct. Ch. Div. 1977). Other courts have rejected a psychological need-to-know without proof of serious psychological disorder as sufficient for good cause to obtain identifying information. See *In re Maples*, 563 S.W.2d 760, 766 (Mo. 1978); *Backes v. Catholic Family & Community Servs.*, 210 N.J. Super. 186, 204-05, 509 A.2d 283, 293 (Super Ct. Ch. Div. 1985); *Bradey v. Children's Bureau*, 275 S.C. 622, 628-29, 274 S.E.2d 418, 422 (1981). One court denied the information to a woman with a severe depressive illness despite her psychiatrist's recommendation that it would benefit her treatment. *In re Dixon*, 116 Mich. App. 763, 771, 323 N.W.2d 549, 552-53 (1982).

200. See *infra* notes 226-62 and accompanying text.

201. OKLA. STAT. ANN. tit. 10, § 57 (West Supp. 1992).

202. Although exact statistics are not available, Jane Connor, program supervisor in charge of adoptions for the Child Welfare Unit of the Oklahoma Department of Human Services, noted that a large percentage of nonrelative adoptions in Oklahoma, perhaps even a slight majority, were independent rather than agency adoptions. Telephone Interview with Jane Connor (Nov. 6, 1990).

Nationally, in 1986, private individuals—as opposed to agencies—handled 31.4% of non-relative domestic adoptions in the U.S. ADOPTION FACTBOOK, *supra* note 86, at 4. It also has been estimated that nationally approximately two-thirds of newborn adoptions are handled independently. ADOPTION LAW AND PRACTICE, *supra* note 76, § 1.05[3], at 1-64 n.31.

203. See, e.g., GA. CODE ANN. § 19-8-23 (Michie 1991); ILL. ANN. STAT. ch. 40, para.

to parents who adopt through private placement, and to children who are adopted in this manner.<sup>204</sup> The private attorneys who handle these adoptions are all licensed to practice law by the state and are thus subject to regulation through disciplinary proceedings for unethical behavior.<sup>205</sup> Allowing them to disclose nonidentifying information should pose no greater threat to the privacy of birth parents than allowing a state or private agency to disclose the same information.

It seems possible that the exclusion of independent adoptions may be an oversight on the state legislatures' part.<sup>206</sup> Even if it is a conscious omission, influenced by a desire to deter independent adoptions, it is extremely unlikely that the omission will prove effective in this regard. Reducing adoptive parents' access to medical information is unlikely to deter birth mothers from placing children through private attorneys. Birth mothers often prefer private adoptions because they feel they have a greater degree of control over placement,<sup>207</sup> because the process feels less institutional and more personal,<sup>208</sup> and because they perceive it as less complicated or intrusive.<sup>209</sup> As long as birth mothers continue to place through independent adoption, the large number of couples desperate to adopt and the shortage of available children<sup>210</sup> dictate that in-

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1522.4 (Smith-Hurd Supp. 1991); N.Y. SOC. SERV. LAW § 373-a (McKinney Supp. 1991); S.C. CODE ANN. § 20-7-1780 (Law. Co-op. Supp. 1990).

204. The National Committee for Adoption estimates that relatively few handicapped or special-needs children are placed through independent adoption, whereas over 50% of the handicapped and special-needs children are placed by public agencies. ADOPTION FACTBOOK, *supra* note 86, at 175. Nevertheless, even children who do not have an obvious handicap or special need at the time of adoption would benefit by disclosure of their genetic and prenatal history. When health problems do occur during childhood or later in life, this information is extremely valuable to accurate diagnosis.

205. *See, e.g.*, Oklahoma Rules Governing Disciplinary Proceedings, OKLA. STAT. ANN. tit. 5, app. 1-A (West 1984 & Supp. 1992) (setting forth Oklahoma rules governing disciplinary proceedings); *see also* Oklahoma *ex rel.* Oklahoma Bar Ass'n v. Stubblefield, 766 P.2d 979, 983 (Okla. 1988) (upholding disciplinary action against attorney for misconduct in connection with independent adoption).

206. Representative Linda H. Larason, cosponsor of the recent amendment in Oklahoma allowing this limited disclosure, states that the application to independent adoptions was not discussed. The bill was requested and drafted by the Oklahoma Department of Human Services. Representative Larason did not know if the legislature would be opposed to having the disclosure provisions apply to private adoptions. In discussing any opposing arguments she could foresee, she suggested that it might be easier to monitor what information is given out if one has more control over the disclosing entity. Telephone Interview with Linda H. Larason, Member, Oklahoma House of Representatives (Aug. 14, 1990).

207. ADOPTION LAW AND PRACTICE, *supra* note 76, § 13.02[3], at 13-58; Gustafson, *supra* note 185, at 851-52.

208. *See* David K. Leavitt, *Counseling Clients in Independent Adoptions*, 6 CAL. CONTINUING EDUC. B. §§ 1-3 (1980).

209. Gustafson, *supra* note 185, at 855-57.

210. The National Committee for Adoption estimates that



dependent adoption will continue to be a highly desirable option for prospective adoptive parents, who view it as an option that may increase their opportunity to adopt and require a shorter waiting period.<sup>211</sup> Wherever independent adoptions remain a legal alternative,<sup>212</sup> access to health-related information should be equal to the disclosure allowed for agency adoptions.

## 2. Stepparent or Relative Adoptions

Several states exclude (or allow for exclusion of) stepparent or relative adoptions from coverage under their mandatory disclosure laws.<sup>213</sup> Presumably the rationale is that a stepparent and the adopted child would have access to health-related information through the stepparent's spouse, who is the adopted child's biological parent. Although it may be true that the stepparent's spouse would know both the child's medical history and his or her own medical and genetic history, the spouse's knowledge of the terminated parent's medical and genetic history may be incomplete. Moreover, since the adoption may terminate the parental rights of one biological parent, including the right to visitation,<sup>214</sup> the

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[a]t least one million American couples with infertility problems and who want a baby will never conceive. These couples compete for and wait for the 50,000 adoptable children who become available each year. The "adoption demand" is such that there are at least 20 prospective adoptive couples per adoptable child.

ADOPTION FACTBOOK, *supra* note 86, at 6.

211. Gustafson, *supra* note 185, at 852. The National Committee for Adoption reports that the usual wait for a healthy white infant through a private agency is two to ten years, and few are available through a public agency. This contrasts with a waiting period of three months to two years for a healthy white infant through independent adoption. ADOPTION FACTBOOK, *supra* note 86, at 175.

212. All but six states apparently allow parents to place their children with unrelated prospective adopters, either through a direct private placement or with the assistance of an intermediary. In the states that do not allow private placements, only licensed state or private agencies are authorized to place children with unrelated prospective adopters. Those six states are Colorado, Connecticut, Delaware, Massachusetts, Michigan, and Minnesota. ADOPTION LAW AND PRACTICE, *supra* note 76, § 1.05[3], at 7 & n.36 (Supp. 1991).

213. See CAL. CIV. CODE § 224.70-76 (West Supp. 1991); IOWA CODE ANN. § 600.16 (West 1981 & Supp. 1991); MONT. CODE ANN. § 40-8-122 (1991); NEB. REV. STAT. § 43-107 (Supp. 1990); OR. REV. STAT. § 109.342 (1991); TEX. FAM. CODE ANN. § 16.032 (West Supp. 1991).

214. See ADOPTION LAW AND PRACTICE, *supra* note 76, § 13.02[1]; HOMER H. CLARK, JR., THE LAW OF DOMESTIC RELATIONS IN THE UNITED STATES § 20.10, at 929 (2d ed. 1988).

Oklahoma's statute on the effect of adoption decrees is typical. It provides in part: After a final decree of adoption is entered, the natural parents of the adopted child, unless they are the adoptive parents or the spouse of an adoptive parent, shall be relieved of all parental responsibilities for said child and shall have no rights over the adopted child or to his property by descent and distribution.

OKLA. STAT. ANN. tit. 10, § 60.16 (West Supp. 1992).

adopted child may lose contact with a biological parent and thus be denied access to medical or genetic information that surfaces after the adoption.<sup>215</sup> Similar problems exist with other adoptions by relatives. The adoptive parents may be unfamiliar with the medical and genetic history of the "other" side of the child's family and, unless the two sides of the family remain in close contact, the child may lose access to future information. Depending upon the circumstances, relatives who adopt also may know far less about the child's medical history than would be available in a stepparent adoption.

Although in stepparent and relative adoptions the concern that the adoptive parent make an "informed choice"<sup>216</sup> may not be paramount, it is nevertheless important to the child's medical and reproductive future that access to health-related information be as complete as possible.<sup>217</sup> Therefore, disclosure statutes should not exclude stepparent and relative adoptions. If a state is particularly concerned with simplifying stepparent adoptions, waiver of the medical and genetic history of the stepparent's spouse (who will continue to be a part of the child's life) should suffice.<sup>218</sup> In addition, statutory provisions for collection and transmis-

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215. A few courts have granted visitation to a biological parent following adoption based on contract, or because it was believed that it would be particularly beneficial to the child under the circumstances. CLARK, *supra* note 214, at 929 & nn.10-12. One court granted visitation rights to an adopted child's sibling, *id.* at 929 n.11, and some states allow grandparent visitation after adoption under limited circumstances, *id.* at 929-30.

216. For a discussion of the importance of informed-choice adoptions, see *supra* notes 134-39, 176 and accompanying text.

217. See *supra* notes 114-29 and accompanying text.

218. One obstacle to including stepparent adoptions in disclosure statutes may be finding an appropriate mechanism to collect the information from a parent whose rights are involuntarily terminated. Often medical and social history is collected as part of the general investigation of the adoptive placement required by statute. See, e.g., IOWA CODE ANN. § 600.8 (West Supp. 1991); MONT. CODE ANN. § 40-8-122 (1991); N.J. STAT. ANN. § 9:3-41.1 (West Supp. 1991); OHIO REV. CODE ANN. § 3107.12 (Anderson 1989). Normally a public or private agency employee or an investigator appointed by the court performs the investigation. See, e.g., MASS. GEN. LAWS ANN. ch. 210, § 50 (Law. Co-op. 1981); MICH. COMP. LAWS ANN. § 710.27 (West Supp. 1991); MONT. CODE ANN. § 40-8-122 (1991); OHIO REV. CODE ANN. § 3107.12 (Anderson 1989). Such statutes often exempt stepparent adoptions. See, e.g., MONT. CODE ANN. § 40-8-122 (1991); OHIO REV. CODE ANN. § 3107.12 (Anderson 1989); TENN. CODE ANN. § 36-1-114(b)(3)(E) (1991); TEX. FAM. CODE ANN. § 16.032 (West Supp. 1991). While the full investigation conducted in nonrelative adoptions may not be necessary, these statutes could easily be amended to require a professional to complete the portion related to collection of health-related information from the parent whose rights are to be terminated. A professional investigator, preferably a licensed social worker, would be better trained and more skilled at eliciting complete and relevant information. See *infra* notes 334-36 and accompanying text. Moreover, contact by a professional might facilitate cooperation that could be absent if the request came from a hostile ex-spouse attempting to terminate involuntarily the rights of the parent from whom information is sought. Although this might involve some added expense to the petitioner, since the investigation is limited, it should not be prohibitively expensive and is worth the cost given the potential benefit to the child in the future. States

sion of postadoption health information should apply to stepparent and relative adoptions so that the adoptee and other biological relatives have access to this vital information.<sup>219</sup>

### 3. Adoptions Subsequent to Involuntary Termination

A few states' disclosure laws are drafted so that they appear to apply only to adoptions in which at least one biological parent voluntarily surrenders the child for adoption.<sup>220</sup> All of the reasons that adoptive parents, children, and other relatives need access to health-related information apply equally to adoptions preceded by involuntary termination of parental rights. Public agencies place the majority of handicapped or special-needs children.<sup>221</sup> Because it is public agencies that most frequently place children following involuntary termination, it is logical to conclude that many such children have special needs. Thus, it is critical that adoption disclosure statutes apply to these adoptions as well.

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concerned about the expense to stepparent petitioners could allow their state social services agencies to perform these investigations on a sliding fee scale.

When this information should be collected may also be problematic. The factors that suggest health information should be disclosed to prospective adoptive parents prior to placement play less of a role in stepparent and relative adoptions in which a pre-established relationship with the child exists and the information is unlikely to affect the adoption decision. Spouses of biological parents or relatives may fear that if they or a third party contacts and seeks participation from the parent to be terminated, the parent may be more likely to challenge the adoption. On the other hand, the court always has the duty to determine whether the grounds to terminate have been proven by clear and convincing evidence, see *Santosky v. Kramer*, 455 U.S. 745, 768-69 (1982), and a termination of parental rights should not be granted in any event unless it is in the best interest of the child. See D. Marianne B. Blair, *Parent-Initiated Termination of Parental Rights*, 24 TULSA L.J. 299, 327-31 (1989) (contending that termination of parent-child relationship without finding that termination is in the best interest of the child deprives the child of constitutional rights). If collection is delayed too long after the adoption, it may be more difficult to locate the biological parent(s) whose rights have been terminated. Moreover, if the information must be collected before the adoption is finalized, the court has greater ability to ensure, for the benefit of the child, that reasonable efforts were made to obtain the information.

If a parent voluntarily consents to termination of parental rights in a stepparent or relative adoption, the parent could be required to provide the necessary information prior to or at the time consent is given, preferably with the assistance of a trained professional.

Kansas recently amended its disclosure statute to include stepparent adoptions among those in which a complete written genetic, medical, and social history of the child and parents should be gathered. See KAN. STAT. ANN. § 59-2130 (Supp. 1990).

219. See *infra* notes 229-45 and accompanying text.

220. LA. REV. STAT. ANN. § 9:422.13 (West 1991); N.J. STAT. ANN. § 9:3-41 (West Supp. 1991).

221. The National Committee for Adoption estimates that more than 50% of the handicapped or special-needs children placed for adoption were placed by public agencies. ADOPTION FACTBOOK, *supra* note 86, at 175.

#### 4. Retroactivity of Newly-Enacted Disclosure Laws

Because mandatory disclosure of health-related information in adoption is a relatively recent statutory phenomenon, it is important to include in these statutes specific provisions mandating disclosure of the nonidentifying social and medical history that is available for adoptions that occurred prior to the enactment of these laws. Although the investigations may not have been as extensive as those that should be mandated by the new statutes,<sup>222</sup> agencies and other intermediaries have for a long time collected at least some information.<sup>223</sup> All of the persons whom current legislation should assist—adoptive parents, adult adoptees, biological descendants and other relatives, and persons whose parents' rights were terminated—are entitled to the same statutory rights to whatever information is available in agency files.<sup>224</sup> In addition, the state agency responsible for adoption investigations for public adoptions, or some other appropriate government entity, should be given the responsibility to conduct an investigation, when medically necessary, to locate biological relatives and acquire information that is not contained in the current files.<sup>225</sup>

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222. See *infra* notes 263-326, 342-409 and accompanying text.

223. See generally *Burr v. Board of County Comm'rs*, 23 Ohio St. 3d 69, 71, 491 N.E.2d 1101, 1104 (1986) (showing that records of agency adoption conducted in 1964 revealed extensive health and social history information that had not been revealed to adoptive parents); *Karwath*, *supra* note 3, at 1, 12 (reporting that agency failed to reveal health information it possessed in 1975, prior to disclosure law taking effect).

224. Although some disclosure statutes are written so broadly that one may infer that persons involved with adoptions taking place prior to enactment might also have disclosure privileges, see, e.g., OHIO REV. CODE ANN. § 3107.17 (Anderson 1989), the better approach is to provide specifically that available information will be released to such persons, see CONN. GEN. STAT. ANN. § 45-68f (West Supp. 1991); ILL. ANN. STAT. ch. 40, para. 1522.24 (Smith-Hurd 1991); IOWA CODE ANN. § 600.16 (West Supp. 1991); N.C. GEN. STAT. § 48-25(d) (1991); N.D. CENT. CODE § 14-15-16(12) (1991); VT. STAT. ANN. tit. 15, § 460(7) (Supp. 1991).

225. See WIS. STAT. ANN. § 48.432(4)(a) (West Supp. 1991). The statute provides:

Whenever any person . . . wishes to obtain medical and genetic information about an individual whose birth parent's rights have been terminated in this state at any time, or whose birth parent consented to his or her adoption before February 1, 1982, or medical and genetic information about the birth parents of such an individual or adoptee, and the information is not on file with the department, the person may request that the department conduct a search for the birth parents to obtain the information. The request shall be accompanied by a statement from a physician certifying either that the individual or adoptee has or may have acquired a genetically transferable disease or that the individual's or adoptee's medical condition requires access to the information.

*Id.*

Because the proposal suggested in the text requires investigations only when medically necessary, the number should not be unduly burdensome for the state social services agency. If such investigations are frequently requested, the legislature must consider allocating funds

### C. *Who Is Entitled To Disclosure?*

#### 1. Adoptive and Prospective Adoptive Parents and Legal Guardians

Recent legislative reform has focused on providing adoptive and prospective adoptive parents access to health-related information.<sup>226</sup> Such disclosure is, of course, critical in order for these parents to provide necessary medical care and meet any special needs that might exist, as well as to assist them with the initial placement decision.<sup>227</sup> Parents, however, are not the only people who may have to make health care decisions for children. If adoptive parents were to die or lose custody of the child, a court (or the parent's will) would name a legal guardian who would then have responsibility for the child's well-being. A legal guardian has equally compelling needs for information about the child because of this duty. Some states have had the foresight to provide equal access to the legal guardian of an adopted child, in order to facilitate appropriate medical treatment under these circumstances.<sup>228</sup>

#### 2. Adult Adoptees

There are equally strong reasons to mandate disclosure of health-related information to the adopted person, at least when she reaches the age of majority and becomes responsible for her own health care.<sup>229</sup> The adoptee's own pre-adoption medical history and the medical and genetic

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necessary to staff this service rather than overwhelm existing governmental social workers who already face huge caseloads.

226. See statutes cited *supra* note 177; see also MISS. CODE ANN. § 93-17-3 (Supp. 1988) (requiring adoptive parents to sign an affidavit acknowledging any abnormal physical or mental condition set forth in doctor's certificate).

Several other states permit disclosure of some health-related information to adoptive parents. See DEL. CODE ANN. tit. 13, § 924 (Supp. 1990); MINN. STAT. ANN. § 259.27 (West Supp. 1992) (inferable from statute); N.M. STAT. ANN. § 40-7-53 (Michie 1989); OKLA. STAT. ANN. tit. 10, § 57 (West Supp. 1992); S.C. CODE ANN. § 20-7-1780 (Law. Co-op. Supp. 1990); TENN. CODE ANN. § 36-1-114 (1991); W. VA. CODE § 48-4-10 (1986 & Supp. 1991).

227. See *supra* notes 114-25, 134-39 and accompanying text.

228. See ARIZ. REV. STAT. ANN. § 8-129 (1989); ARK. CODE ANN. § 9-9-505 (Michie 1991); ME. REV. STAT. ANN. tit. 19, § 534 (West Supp. 1990); MO. ANN. STAT. § 453.121 (Vernon Supp. 1991); TEX. FAM. CODE ANN. § 16.032 (West Supp. 1991); WIS. STAT. ANN. § 48.432 (West Supp. 1991) (guardian or legal custodian). UTAH CODE ANN. § 78-30-17 (1987) specifically provides that access to the health history, genetics, and social history shall be available to the adoptee's legal guardian "in the event of the death of the adoptive parents." *Id.*

229. The response of state adoption agencies to a survey on the release of adoption information indicated they received fairly frequent requests from adult adoptees for information about their genetic background. Plumridge et al., *supra* note 126, at 208-12. In Minnesota, during a 13-month period after a law went into effect opening sealed birth certificates, 56% of the adults who filed requests for birth certificates asked for information on their genetic histories. Black, *supra* note 85, at 198.

history of her birth parents and other biological relatives will be relevant to diagnosis and medical treatment throughout the adoptee's lifetime, not just during childhood.<sup>230</sup>

Many states assume that adoptive parents will transmit information to their child. Adults who have been adopted, however, are entitled to information about their backgrounds that is as complete as possible and not filtered through the memory or discretion of adoptive parents. Although ideally adoptive parents should keep a copy of all medical and social background information provided to them, this may not be possible because the information is not always disclosed in writing.<sup>231</sup> Due to the excitement and anxiety that are typically present when prospective adoptive parents meet with a social worker or adoption intermediary to discuss a potential placement or finalize an adoption, not to mention the passage of many years, it is entirely possible that by the time the child reaches majority, the adoptive parents' memory may be incomplete.<sup>232</sup> In addition, adoptive parents might choose not to disclose important information to their adopted child for a variety of reasons. They might desire to protect the child from information they perceive as unpleasant or disturbing; finding it psychologically threatening, they might be uncomfortable discussing the adoptee's biological family at all;<sup>233</sup> they might fear that somehow the information could help the adoptee trace the biological family; or they could have a particularly strong desire to have (or not have) grandchildren.

As an adult, it is the adopted person, not the parents, who must convey relevant medical and genetic history to medical personnel. It is the adoptee who must consider this information when making choices about childbearing. Thus, adult adoptees need complete and accurate information and should not be forced to rely upon the memory or preferences of their adoptive parents.<sup>234</sup> Moreover, information that becomes

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230. Black, *supra* note 85, at 198.

231. For a discussion of the advantages of written disclosure, see *infra* notes 471-73 and accompanying text.

232. SOROSKY et al., *supra* note 77, at 37 ("It has been of concern to adoption workers stressing openness that many adoptive parents forget what they know about background information once placement has occurred, therefore much of the information is never transmitted to the children.").

233. *Id.* One adoptive couple, for example, could not bear to tell their adopted son he had siblings in his birth family, because they feared it would create resentment on his part that he was an only child in their family. *Id.* at 21. See generally FLORENCE FISHER, *THE SEARCH FOR ANNA FISHER* (1973) (one adoptee's narration of her parent's efforts to keep from her the fact that she was adopted).

234. It might be argued that children raised by their biological parents must rely upon their parents to transmit medical and genetic history. Memory impairment, however, would be less of a threat because it is the biological parents' own medical and genetic history that is con-

available after the adopted person reaches majority should be transmitted directly to the adoptee.<sup>235</sup>

Although the majority of states have mandated the direct disclosure of health-related information to adoptees,<sup>236</sup> a significant number have yet to include this provision in their statutes.<sup>237</sup> It is noteworthy that

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veyed, not someone else's. The biological parent normally would be totally familiar with the child's own medical history, unlike an adoptive parent who was not present for the prenatal period, or normally for birth, nor for any medical treatment required prior to placement. Furthermore, other members of the family in addition to biological parents, are accessible, a factor absent in nonrelative adoptions.

235. Since many states keep information for 99 years after the adoption, *see, e.g.*, ARK. CODE ANN. § 9-9-505 (Michie 1991), the adoptive parents would be unlikely to be alive to transmit it to the adoptee or the adoptee's descendants. The adoptive person not only has a right to have access to the information, but should also be advised of the opportunity to report medical and genetic information to the appropriate authority if it would be relevant to other biological relatives. *See infra* notes 251-59 and accompanying text. This is more likely to occur if the adopted adult has direct access to information.

236. At present, the following states provide for mandatory disclosure of some medical or social information to adoptees: ALA. CODE § 26-10A-31 (Supp. 1991) (19 or older); ALASKA STAT. § 18.50.500 (1991) (18 or older); ARIZ. REV. STAT. ANN. § 8-129 (1989) (18 or older); ARK. CODE ANN. § 9-9-505 (Michie 1991) (18 or older); CAL. CIV. CODE § 224.73 (West Supp. 1991) (18 or older or married); CONN. GEN. STAT. ANN. § 45a-746 (West Supp. 1991) (adult); FLA. STAT. ANN. § 63.162 (West Supp. 1991) (adult); GA. CODE ANN. § 19-8-23 (Michie 1991) (21 or older); HAW. REV. STAT. § 578-14.5 (Supp. 1990) (upon majority); ILL. ANN. STAT. ch. 40, para. 1522.4 (Smith-Hurd Supp. 1991) (18 or older); IND. CODE ANN. § 31-3-4-14 (Burns 1987) (no age restriction); IOWA CODE ANN. § 600.16 (West Supp. 1991) (adult); KAN. STAT. ANN. § 59-2122 (Supp. 1990) (adult); KY. REV. STAT. ANN. § 199.520 (Michie/Bobbs-Merrill 1991) (adult); LA. REV. STAT. ANN. § 9:422.13 (West 1991) (18 or older); MASS. GEN. LAWS ANN. ch. 210, § 5D (Law. Co-op. Supp. 1991) (18 or older); MICH. COMP. LAWS ANN. § 710.68(7) (West Supp. 1991) (18 or older); MINN. STAT. ANN. § 259.47 (West Supp. 1992) (implies 19 or older); MO. ANN. STAT. § 453.121 (Vernon Supp. 1991) (21 or older); NEB. REV. STAT. § 43-146.02 (1988) (no age provision); N.H. REV. STAT. ANN. § 170-B:19 (1990 & Supp. 1991) (21 or older); N.M. STAT. ANN. § 40-7-53 (Michie 1989) (18 or older); N.Y. SOC. SERV. LAW § 373-a (McKinney Supp. 1991) (adopted, former foster child; when discharged to own care); N.C. GEN. STAT. § 48-25(e) (1991) (age 21); N.D. CENT. CODE § 14-15-16 (1991) (adult); OHIO REV. CODE ANN. § 3107.17 (Anderson 1989) (age of majority); OR. REV. STAT. § 109.342 (1991) (age of majority); S.D. CODIFIED LAWS ANN. § 25-6-15.2 (Supp. 1991) (18 or older); TEX. FAM. CODE ANN. § 16.032(2)(i)(3) (West Supp. 1991) (adult); UTAH CODE ANN. § 78-30-17 (1987) (no age restriction); VT. STAT. ANN. tit. 15, § 461(a) (1989) (no age restriction); WIS. STAT. ANN. § 48.432 (3)(a)(1) (West Supp. 1991) (18 or older); WYO. STAT. § 1-22-116 (1988) (age of majority).

Other states allow the release of nonidentifying medical or social information to adoptees at agency discretion or upon court order. *See* ME. REV. STAT. ANN. tit. 19, § 534 (West Supp. 1990) (18 or older); MD. FAM. LAW CODE ANN. § 5-329(a)(1) (Supp. 1991) (no age restriction); PA. STAT. ANN. tit. 23, § 2905 (1991) (18 or older); S.C. CODE ANN. § 20-7-1780(D) (Law. Co-op. Supp. 1990) (no age restriction); TENN. CODE ANN. § 36-1-131(a) (1991) (no age provision); WASH. REV. CODE ANN. § 26.33.340 (West Supp. 1991) (no age restriction); W. VA. CODE § 48-4-10(a) (1986 & Supp. 1991) (no age restriction).

237. The jurisdictions with no provision for disclosure of medical or social background information to the adoptee are Colorado, Delaware, Idaho, Mississippi, Montana, New Jersey, Oklahoma, Rhode Island, Virginia, and the District of Columbia.

Ohio recognizes the autonomy of adopted persons by providing that after the adoptee reaches the age of majority, the social and medical history forms can no longer be disclosed to the adoptive parents. Only the adoptee may inspect the forms.<sup>238</sup>

### 3. Descendants of Adoptees

Biological descendants of an adoptee have a strong interest in access to medical and genetic information that might be relevant to their own medical diagnosis, treatment, and childbearing decisions. Many genetic conditions, for example, skip generations; the adoptee could be symptom-free, providing her children with no clue as to their risk.<sup>239</sup> Unlike descendants of unadopted persons, descendants of adoptees frequently do not have access to other biological relatives who could provide the information,<sup>240</sup> and thus a mechanism must be created to facilitate their access to important medical data.

States should provide, as only a handful have done,<sup>241</sup> that adult descendants of the adoptee have access to relevant medical information under specified circumstances. Information about hereditary factors that could affect an adoptee's children or their offspring certainly would be relevant. On the other hand, disclosure of information that has no hered-

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238. OHIO REV. CODE ANN. § 3107.17 (Anderson 1989).

239. For example, autosomal recessive conditions such as sickle cell anemia, cystic fibrosis, or phenylketonuria, and X-chromosome-linked recessive conditions, such as hemophilia, Duchenne Muscular Dystrophy, or X-linked retardation, do not appear in every generation. Catherine A. Reiser, *Basic Principles of Genetics: A Human Approach*, in GENETIC FAMILY HISTORY, *supra* note 1, at 63, 65-66.

240. Contemporary adoption statutes still reflect the traditional concept that once an adoption is final, the child's biological relatives have no right to any further personal or legal role in the adoptee's life. ADOPTION LAW AND PRACTICE, *supra* note 76, § 13.02[1]. In recent years some adoption specialists have advocated open adoption to varying degrees. *Id.* § 13.02[3], at 13-56 to 13-57. The argument has been most forceful in relation to the adoption of older children who have had some relationship with their birth families. *Id.* § 13.02[2], at 13-53 to 13-54, § 13.02[3], at 13-64, 13-70. Nevertheless, it is estimated that open adoption involving postadoption contact with birth parents in nonrelative adoptions is still infrequent. *Id.* § 13.02[3], at 13-60. Although grandparents under certain conditions have been awarded visitation following a step parent adoption, *id.* § 13.03[3](a), app. 1-A, at 1A-10 to 1A-11, generally when adopters are unrelated to the child, grandparents have no right to such visitation absent a prior visitation or custody order. *Id.* § 13.03[4], at 13-97.

241. See ARIZ. REV. STAT. ANN. § 8-129(B)(3)(d) (1989) (to any progeny after adoptee's death); CAL. CIV. CODE § 1798.24(s) (West Supp. 1991) (to child or grandchild; death of adoptee not required); CONN. GEN. STAT. ANN. § 45a-746 (West. Supp. 1991) (to adult descendants after adoptee's death); ME. REV. STAT. ANN. tit. 19, § 534 (West 1981 & Supp. 1990) (to all descendants on petition to the court; death of adoptee not required); OR. REV. STAT. § 109.500(1)(d)(B) (1991) (to any progeny of the adoptee 18 or older; upon death of adoptee); TEX. FAM. CODE ANN. § 16.032(i)(5) (West Supp. 1991) (to adult progeny after adoptee's death); UTAH CODE ANN. § 78-30-17(4)(e) (1987) (to child or descendant, no age restriction).



itary effect may unjustifiably invade the privacy of the birth family.<sup>242</sup> If the adoptee is deceased, relevant information should be disclosed to adult descendants without a court order. In addition, a spouse or guardian who has legal custody of an adoptee's minor children after the adoptee's death also should have access to relevant medical and genetic information to facilitate medical diagnosis and care of these children.<sup>243</sup>

If the adoptee is still alive, however, bypassing her to allow descendants access to the adoptee's medical or social history could invade the adoptee's right to privacy under circumstances in which an unadopted person's privacy would not be similarly invaded.<sup>244</sup> Access to this information while the adoptee is alive and without the adoptee's consent should be allowed only by court order upon a showing of medical necessity for the information.<sup>245</sup>

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242. Under both constitutional and tort doctrines, information deemed personal can be released if there is a reasonable public interest in doing so and procedures guard against unwarranted disclosure. See *supra* notes 70-75 and accompanying text. Although much of the information contained in the medical and social history will have a hereditary effect, some very personal information will not. Child abuse to the adoptee, HIV infection of a birth mother, and in some cases the reason for adoptive placement, may be examples. While there is psychological justification for adoptees to have background that goes beyond information of hereditary factors, that justification diminishes greatly when applied to descendants and would not outweigh the birth family's privacy interests. By the time a descendant is an adult, it is quite possible that the birth family will be known to descendants, if contact has been made by an adoptee through registry or mutual consent statutes. See *supra* notes 94-96 and accompanying text.

There is a risk in allowing the history to be screened for hereditary information only, however. The person who screens, if not properly trained, may be unaware of the hereditary impact of many factors, such as alcoholism or breast cancer, and may therefore screen out too much.

243. The following states have enacted such a provision: ARIZ. REV. STAT. ANN. § 8-129(B)(a)(c) (1989) (spouse or legal guardian); ARK. CODE ANN. § 9-9-505(2)(c) (Michie 1991) (spouse or legal guardian); OR. REV. STAT. § 109.500(1)(d)(A) (1991) (spouse); TEX. FAM. CODE ANN. § 16.032(i)(4) (West Supp. 1991) (spouse); UTAH CODE ANN. § 78-30-17(4)(d) (1987) (spouse).

244. In defining the right to privacy and medical confidentiality under tort law, courts have determined that immediate family members do not have an automatic right to access to their relatives' medical files. See Marlene Huggins et al., *Ethical Dilemmas Arising During Predictive Testing for Adult-Onset Disease: The Experience of Huntington Disease*, 47 AM. J. HUM. GENETICS 4, 5-6 (1990). See generally Zelin, *supra* note 58, at 678, 711-12 (summarizing cases in which court addressed potential liability for disclosure to patient's spouse). Some courts have refused to find liability, however, when a physician releases information to a patient's spouse. See, e.g., *Mikel v. Abrams*, 541 F. Supp. 591, 598 (W.D. Mo.), *aff'd without opinion*, 716 F.2d 907 (8th Cir. 1983); *Curry v. Corn*, 52 Misc. 2d 1035, 1037, 277 N.Y.S.2d 470, 472 (Sup. Ct. 1966); Zelin, *supra* note 58, at 711-12. But see *MacDonald v. Clinger*, 84 A.D.2d 482, 488, 446 N.Y.S.2d 801, 805 (1982) (holding that disclosure by psychiatrist to patient's wife of intimate statements by patient is actionable breach of fiduciary duty of confidentiality).

245. Although an adoptee's need for privacy must be respected, courts also have recognized a privilege to disclose otherwise confidential or private information to prevent harm to others. *Tarasoff v. Regents of Univ. of Cal.*, 17 Cal. 3d 425, 450, 551 P.2d 334, 347, 131 Cal.

#### 4. Unadopted Children Whose Parents' Rights Are Terminated

Disclosure issues similar to those discussed above arise in the context of children whose biological parents' rights have been terminated but who were never adopted. One state refers to these individuals as "adoptable persons."<sup>246</sup> Upon reaching adulthood, they also require access to their medical, genetic, and social background information for all the same reasons it should be provided to adoptees. Their offspring may also require genetic information after their death because other avenues of acquiring it (such as through relatives) may be foreclosed as a result of severed ties. Each state should consider following the lead of Connecticut and Wisconsin, which have provided in their disclosure statutes that persons whose parents' rights were terminated but who were never adopted have the same access to medical records as adoptees,<sup>247</sup> and should provide equivalent disclosure to their descendants<sup>248</sup> and other biological<sup>249</sup> relatives.<sup>250</sup>

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Rptr. 14, 27 (1976); *Humphers v. First Interstate Bank*, 298 Or. 706, 720, 696 P.2d 527, 535 (1985); see *supra* notes 64, 70-75 and accompanying text.

The conflict between the duty of confidentiality to a patient and the duty to warn third parties also is a source of current concern among medical ethicists, both nationally and internationally. In a recent questionnaire mailed to medical geneticists in 18 countries, to which 677 (64%) responded, 58% (63% outside the United States) replied that the duty to warn relatives at risk overrides the duty of confidentiality to a patient discovered to have Huntington's Disease who has refused to permit disclosure of the diagnosis to relatives at high risk for the same disorder. Similarly 60% (66% outside the United States) would warn relatives of the diagnosis of a patient with hemophilia A who refused to permit disclosure. Dorothy C. Wertz et al., *Medical Geneticists Confront Ethical Dilemmas: Cross-cultural Comparisons Among 18 Nations*, 46 AM. J. HUM. GENETICS 1200, 1208 (1990); see also Marguerite A. Chapman, *Invited Editorial: Predictive Testing for Adult-Onset Genetic Disease: Ethical and Legal Implications of the Use of Linkage Analysis of Huntington Disease*, 47 AM. J. HUM. GENETICS 1, 2 (1990) (Experts in medical ethics have explored the option of making access to genetic testing conditional on prior agreement to disclose information to other at-risk relatives who need the data for their own risk assessment.). When information is essential to proper diagnosis and treatment of biological descendants, the court should have the power to make it available.

246. See CONN. GEN. STAT. ANN. § 45a-743(1) (West Supp. 1991) (providing that statute applies only to those persons to whom the parental rights of both the biological father and mother have been terminated).

247. See *id.* § 45a-746(4); WIS. STAT. ANN. § 48.432(3) (West Supp. 1991). The Wisconsin statute is broader than the Connecticut statute because it also applies when only one parent's rights have been terminated. This approach is preferable, as access to medical information from that side of the family presumably would be affected by the termination.

248. See CONN. GEN. STAT. ANN. § 45a-746(5) (allowing disclosure of information to adult descendants of adoptable persons after the death of the adoptable person); WIS. STAT. ANN. § 48.432(3)(a)(4) (allowing disclosure at any time to offspring of individuals whose birth parent's rights have been terminated in the state).

249. See WIS. STAT. ANN. § 48.432(7)(b) (requiring notice to a birth parent whose rights to a child were terminated that the child has acquired or may have a genetically transferable disease).

250. The disclosure of medical, genetic, and social background information to foster par-

## 5. Birth Family

Disclosure statutes should also permit members of the adoptee's biological family to have access to genetically significant information about the adoptee or the adoptee's descendants that is voluntarily provided to the recordkeeper<sup>251</sup> after the relinquishment.<sup>252</sup> Information that an adopted child or descendants have been diagnosed with a hereditary condition may significantly affect the medical diagnosis, treatment, and childbearing plans of birthparents, biological siblings, and other relatives.<sup>253</sup> For example, one physician reported examining an adopted child with a probable diagnosis of a mild form of Meckel Syndrome, a generally lethal genetic illness. Due to the current level of secrecy in the adoption process, she was unable to alert the birth parents to the risks of future childbearing.<sup>254</sup> Even if some genetic disorders already are known to exist in the family, assessing one family member's risk for certain diseases, such as Huntington's Disease,<sup>255</sup> often requires the development of a complete family pedigree identifying the other family members who have developed this disease.<sup>256</sup> Lack of information about biological siblings or other family members could alter significantly the results of the predictive testing.<sup>257</sup> Moreover, allowing biological parents access to the medical and social history records affords them an opportunity to make corrections or supply missing information.<sup>258</sup> Several states have recog-

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ents, legal guardians, or other caregivers for children whose parents' rights have been terminated is beyond the scope of this Article. It should be noted that although such disclosure would not involve all of the same considerations that affect disclosure to adoptive parents, such individuals require much of this information in order to provide the child with appropriate medical treatment and care. Wisconsin does provide that guardians or legal custodians of children whose birth parent's rights have been terminated should have access to medical information about the child and the child's birth parents. *Id.* § 48.432(3)(a)(3) (West Supp. 1991).

251. For a discussion of the need to impose a statutory duty on adoption agencies and other intermediaries to maintain new or corrected information made available after an initial investigation has been completed, see *infra* notes 454-62 and accompanying text. For a discussion of a proposed duty to transmit updated information, see *infra* notes 477-85 and accompanying text.

252. Such provisions should include biological relatives of unadopted persons who were the subject of termination proceedings. See *supra* notes 246-50 and accompanying text.

253. Plumridge et al., *supra* note 126, at 209; see also Reiser, *supra* note 239, at 65-66 (describing autosomal and X-linked recessive conditions that skip generations).

254. Lamport, *supra* note 4, at 114.

255. Huntington's Disease, also called Huntington's Chorea, is a chronic degenerative neurological disease characterized by spasmodic involuntary movements and intellectual deterioration, ending in dementia. *STEDMAN'S MEDICAL DICTIONARY*, *supra* note 121, at 299.

256. Chapman, *supra* note 245, at 1; Huggins et al., *supra* note 244, at 6; Lamport, *supra* note 4, at 113.

257. See Huggins et al., *supra* note 244, at 6.

258. For example, OHIO REV. CODE ANN. § 3107.12(D)(4) (Anderson 1989), provides that a biological parent or any other person who provided information to assist in preparation

nized the need for disclosure of some medical information to birth parents, siblings, or other relatives of the adoptee,<sup>259</sup> but the majority have neglected this group.

## 6. Medical Personnel

A small number of states allow an agency or the court discretion to release information to a provider of medical services.<sup>260</sup> Direct release to medical caregivers after adoption should be limited to circumstances in which the adult adoptee, an adoptive parent or legal custodian of a minor adoptee, or the patient who is related to the adoptee is not capable of requesting the information directly. A provision for direct release may be useful for emergencies,<sup>261</sup> but direct release to medical personnel should never be contemplated as a substitute for release of information to the patient involved or the minor patient's parent or custodian. Such a substitution, absent an emergency, would deny the autonomy of adoptive

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of the social and medical histories of the biological parents may correct or expand the histories to include different or additional types of information. Presumably, they would need to see the original record to correct it. To protect privacy, persons other than the biological parent should see only the information they contributed.

259. See ALA. CODE § 26-10A-31(G)(2) (Supp. 1991) (birth parents); ARIZ. REV. STAT. ANN. § 8-129(3)(e) (1989) (birth parents or other biological children of birth parents); ARK. CODE ANN. § 9-9-505(b)(2)(D) (Michie 1991) (birth parents); COLO. REV. STAT. § 19-5-207(3) (Supp. 1991) (birth parents); IND. CODE ANN. § 31-3-4-6(2), -6(4), -14(a)(1) (Burns 1987) (birth parents and relatives of birth parents); MASS. ANN. LAWS ch. 210, § 5D(2) (Law. Co-op. 1981) (birth parents); MICH. COMP. LAWS ANN. § 710.68a(2) (West Supp. 1991) (birth parents and adult siblings); MINN. STAT. ANN. § 259.47(1) (West 1982 & Supp. 1992) (birth parents and adult siblings); OR. REV. STAT. § 109.500(1)(b) (1991) (birth parents); UTAH CODE ANN. § 78-30-17(4)(f)-(g) (1987) (birth parents and adult siblings); WASH. REV. CODE ANN. § 26.33.340 (West 1986 & Supp. 1991) (birth parents).

S.C. CODE ANN. § 20-7-1780(D) (Law. Co-op. 1985 & Supp. 1990) and WASH. REV. CODE ANN. § 26.33.340 (West 1986 & Supp. 1991) make release of medical information to birth parents discretionary.

Although some states indirectly allow relatives access by allowing anyone with a need for the information to seek a court order, see ALA. CODE § 26-10A-31(a) (Supp. 1991); TENN. CODE ANN. § 36-1-131(a) (1991), this general legislation fails to recognize the specific interests of biological relatives. If only nonidentifying information is supplied without a court order (a court order may be appropriate if identifying information is needed), and the information presumably is provided voluntarily to the entity retaining records by the adoptive parent or adoptee, it seems unnecessary to impose the expense of obtaining a court order and to subject the disclosure to the discretion of the court.

260. See GA. CODE ANN. § 19-8-23(d) (Michie 1991) (providing that agency may petition court to release medical information to provider of medical services or to a party of interest in the adoption); IOWA CODE ANN. § 600.16(1)(c) (West 1981) (medical history may be released to any person approved by the department for the purpose of treating a patient in a medical facility); NEB. REV. STAT. § 43-146.03 (1988) (court may order release of information on birth certificate on request of licensed doctor or psychologist if necessary to treat an adoptee).

261. An obvious example would be an adult adoptee who lapses into a coma or uncontrolled seizures, the cause of which is undiagnosed.

parents, adult adoptees, and their biological relatives.<sup>262</sup>

#### D. Content of Information Collected and Disclosed

##### 1. Medical History of the Child

Surprisingly, many states in their adoption disclosure statutes omit reference to obtaining and transmitting information about the child's own medical history.<sup>263</sup> Perhaps this oversight occurred because adoption statutes are often drafted with a focus on the adoption of newborn infants.<sup>264</sup> Although that is the image that the public often carries of nonrelative adoption, infant adoptions in fact comprise slightly less than half of all domestic unrelated adoptions.<sup>265</sup> Moreover, even newborns have a medical history—their prenatal and neonatal records—that can be vital to their care. It is extremely important that a complete medical history of a child be transmitted to prospective adoptive parents, so they can make a realistic assessment of their ability to meet the child's special needs, and so that they can obtain any medical or psychological treatment the child may need.<sup>266</sup> Because early medical history can be relevant to diagnosis throughout a person's lifetime, it also should be available to the adult adoptee.<sup>267</sup>

Although it is probably unnecessary and cumbersome for every relevant disease or condition to be listed in the statute,<sup>268</sup> statutes regulating

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262. In addition to the categories of persons discussed above, it is interesting to note that Iowa authorizes its department of human services to approve the release of nonidentifying health information on adoptees to persons for the sole purpose of conducting legitimate research projects. See IOWA CODE ANN. § 600.16(1)(C) (West 1981).

263. The following states with disclosure statutes omit reference to the inclusion of the child's medical history: Alaska, Arizona, Connecticut, Georgia, Illinois, Kentucky, Louisiana, Maine, Missouri, Montana, New Hampshire, North Carolina, North Dakota, South Dakota, Vermont, and West Virginia.

In addition, Hawaii includes only medical records relating to the birth of the child. HAW. REV. STAT. § 578-14.5(a) (Supp. 1990).

264. See UNIF. ADOPTION ACT prefatory note at 1, 3 (Tentative Draft 1990). The prefatory note observes that most states' adoption laws "address the consensual adoption of presumably healthy newborns or young children by unrelated adults, and leave the characteristics of other kinds of adoption to be ferreted out and pieced together from negative inferences from statutory language intended to deal with the adoption of unrelated infants." *Id.*

265. The National Committee for Adoption reports that 48.1% of all unrelated adoptions of children born in the United States were infants. ADOPTION FACTBOOK, *supra* note 86, at 4.

266. See *supra* notes 104-25, 133-39 and accompanying text.

267. See *supra* notes 126-29 and accompanying text.

268. Detailed administrative regulations or distribution by a state agency of well-researched forms to use for collection can facilitate the collection of a comprehensive history. For example, an excellent pair of forms was developed in 1984 for the Wisconsin Department of Human Services, with the assistance of the Wisconsin Clinical Genetics Center. See Division of Community Services, Wisconsin Department of Health and Social Services, Form No.

collection should specify more than simply "the medical history of the child." Prenatal and neonatal information should be specifically required.<sup>269</sup> The prenatal history and the history of labor, delivery, and neonatal evaluation and testing are essential to risk analysis, diagnosis, and treatment of many subsequent problems.<sup>270</sup> Studies have estimated that twenty percent of birth defects may be related to drug or alcohol ingestion or poor prenatal care of the expectant mother.<sup>271</sup> For example, consumption of alcohol during pregnancy may create a risk of fetal alcohol syndrome, characterized by growth retardation, mental retardation, a small head, and particular facial characteristics.<sup>272</sup> The only way to confirm the presence of this syndrome is to obtain accurate information about the quantity and nature of the alcohol that the mother consumed while pregnant.<sup>273</sup> Sudden, rapid weight gain by the mother during the

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DCS-149, Family History Questionnaire: Medical/Genetic (Nov. 1984) [hereinafter Wisconsin Medical/Genetic Form]; Division of Community Services, Wisconsin Department of Health and Social Services, Form No. DCS-149A, Family History Questionnaire: Medical/Genetic—Pregnancy and Delivery (Nov. 1984) [hereinafter Wisconsin Pregnancy & Delivery Form]. The forms are available by writing to Joan K. Burns, Project Director, Wisconsin Clinical Genetics Center, 1500 Highland Ave., Room 331, University of Wisconsin, Madison, WI 53706. Another sample medical history form is currently being developed by Diane Plumridge, MSW, project coordinator of the Pacific Northwest Regional Genetics Group, and was scheduled to be presented to the American Society of Human Genetics and the American Academy of Pediatrics by mid-October, 1990. Letter from Diane M. Plumridge, Project Coordinator, Pacific Northwest Regional Genetics Group, to D. Marianne B. Blair (Aug. 22, 1990).

269. Currently only nine states specifically require prenatal or prenatal and neonatal information to be collected and disclosed. See HAW. REV. STAT. § 578-14.5 (a)-(h) (Supp. 1990); IND. CODE ANN. § 31-3-4-14(1)-(3) (Burns 1987); N.J. STAT. ANN. § 9:3-41.1 (West Supp. 1991); N.Y. SOC. SERV. LAW § 373-a (McKinney Supp. 1991); OKLA. STAT. ANN. tit. 10, § 60.5A(A) (West 1987); OR. REV. STAT. § 109.342(2)(a) (1991); TEX. FAM. CODE ANN. § 16.032(a)-(c) (West Supp. 1991); WIS. STAT. ANN. § 48.432 (West 1987 & Supp. 1990); WYO. STAT. § 1-22-116 (1988 & Supp. 1991).

270. See Don Hadley & Barbara Petterson, *Family History Workshop*, in GENETIC FAMILY HISTORY, *supra* note 1, at 100, 108; Renata Laxova, *Minor Signs of Major Problems*, in GENETIC FAMILY HISTORY, *supra* note 1, at 69, 72; O'Connell, *supra* note 92, at 534.

271. O'Connell, *supra* note 92, at 534 n.14 (citing letter from Professor Stella B. Kontras, M.D., Ohio State University College of Medicine, to Ohio State Senator O'Shaughnessy (Feb. 22, 1978)).

272. Laxova, *supra* note 270, at 72. A few states specify by statute that information on drug and/or alcohol consumption be indicated in the medical history. See N.J. STAT. ANN. § 9:3-41.1(a) (West Supp. 1991); OKLA. STAT. ANN. tit. 10, § 60.5A(A)(2)(b) (West 1987); WYO. STAT. § 1-22-116 (1988).

273. Laxova, *supra* note 270, at 72. This is only one example of many environmental factors during pregnancy that can affect the health of the child. Much has been written in recent years about the plight of "crack babies" and the horrible effects they suffer from their mothers' drug ingestion. See, e.g., Dorothy E. Roberts, *Punishing Drug Addicts Who Have Babies: Women of Color, Equality, and the Right of Privacy*, 104 HARV. L. REV. 1419, 1429-30 (1991); Laurie Rubenstein, Note, *Prosecuting Maternal Substance Abusers: An Unjustified and Ineffective Policy*, 9 YALE L. & POL'Y REV. 130, 133-35 (1991). Certainly ingestion of other street drugs creates risks for the child as well. See Mary K. Kennedy, Note, *Maternal Liability for*

pregnancy also can signal future health problems for the child.<sup>274</sup> Low birth weight may be a predictor of future medical, psychological, or developmental abnormalities.<sup>275</sup> Minor abnormalities at birth, such as an extra finger and a small piece of extra skin about the ear, may be signs that a baby is at high risk for more severe medical problems.<sup>276</sup> Such examples illustrate the importance of collecting prenatal and neonatal information, which might be overlooked if the topic is not included in the statute.

Several other categories of information related to the medical history of the child should be specifically identified in the disclosure statutes. Information regarding the child's medical problems, including diseases, illnesses, accidents, allergies, and congenital defects,<sup>277</sup> and a history of medical treatment, including hospitalizations and surgeries, immunization records, the results of significant diagnostic testing,<sup>278</sup> and

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*Prenatal Injury Arising from Substance Abuse During Pregnancy: The Possibility of a Cause of Action in Pennsylvania*, 29 PA. ISSUE 553, 556 (1991).

Ingestion by the mother of prescription drugs can also create risks for the child. For example, fetal Dilantin syndrome, which consists of prenatal growth deficiency, microcephaly, and mental deficiency, can sometimes result from the mother's ingestion of Dilantin, an anti-epileptic drug, during pregnancy. PHYSICIAN'S DESK REFERENCE 1600 (44th ed. 1990); Laxova, *supra* note 270, at 77.

The Family History Questionnaire developed by the Wisconsin Clinical Genetics Center inquires about medications, including prescription, over-the-counter, and street drugs taken during pregnancy; cigarette smoking; alcohol consumption, including the kind of alcohol consumed and the number of drinks per day for each trimester of pregnancy; and whether the mother was exposed to unusual fumes or chemicals (through work or otherwise), X-rays, or other forms of radiation during pregnancy. See Wisconsin Medical/Genetic Form, *supra* note 268; Wisconsin Pregnancy & Delivery Form, *supra* note 268; see also Hadley & Petterson, *supra* note 270, at 108 (listing information that should be collected in a pregnancy history). The trimester during which the exposure occurs will indicate the type of damage for which the fetus may be at risk. Hadley & Petterson, *supra* note 270, at 108.

274. Laxova, *supra* note 270, at 74.

275. *Id.* at 72. A low birth-weight baby is not necessarily premature. *Id.* at 72, 74.

276. *Id.* at 74.

277. See, e.g., OKLA. STAT. ANN. tit. 10, § 60.5A(A)(1)(b) (West 1987) (diseases, disabilities, birth defects); OR. REV. STAT. § 109.342(2)(a) (1991) (diseases, accidents, allergies, birth defects); WASH. REV. CODE ANN. § 26.33.350(2)(a) (West Supp. 1991) (medical history, X-rays, examinations, hospitalizations, immunizations of child and birth family).

278. For example, the results of the normal newborn screening tests for phenylketonuria, hypothyroidism, and any others that may have been performed always should be included and disclosed. See *Foster v. Bass*, 575 So. 2d 967, 971-72 (Miss. 1990) (reporting that adopted child suffered permanent brain damage resulting in severe retardation due to pediatrician's lack of awareness that phenylketonuria test had not been performed prior to transfer of custody of newborn to adoptive parents). Even if the test results are negative, later caregivers such as adoptive parents need to know this so that the tests will not be unnecessarily repeated. It should not be necessary to report every *negative* culture for a strep throat, for example, but the results of any laboratory, X-ray, or other diagnostic test that would assist further medical personnel in diagnosis or treatment should be included.

dental treatment, should be required to be collected and transmitted.<sup>279</sup> A developmental history, tracing the age at which the child acquired basic gross motor, fine motor, speech/language, and congenitive skills, should be included.<sup>280</sup> The statutes must mandate inclusion of psychological or psychiatric evaluations of the child and a record of psychiatric or psychological treatment,<sup>281</sup> because this is precisely the type of information that has been susceptible to selective nondisclosure in the past.<sup>282</sup> Texas's disclosure statute has a very useful provision that requires collection, retention, and disclosure of "any information necessary to determine whether the child is entitled to or otherwise eligible for state or federal financial, medical, or other assistance."<sup>283</sup> Although most of that information would be provided under the general description of medical history, such a provision places squarely on the entity responsible for collection and disclosure the obligation to ensure that adoptive families be given all the information they need to apply for such assistance, and may require greater efforts to obtain that information, if it is not readily available.<sup>284</sup>

## 2. Medical and Genetic History of Parents and Other Biological Relatives

The vast majority of states require collection and disclosure of the medical history of the biological parents.<sup>285</sup> The medical history of the

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279. See, e.g., TEX. FAM. CODE ANN. § 16.032(b) (West Supp. 1991); WASH. REV. CODE ANN. § 26.33.350(1). It would be extremely useful to make all previous medical records of older children, with identifying information extracted, available to adoptive parents in order to provide current physicians, dentists, and other medical personnel with a complete history, if those records are available.

280. See, e.g., CAL. CIV. CODE § 222.26(a) (West Supp. 1991); N.J. STAT. ANN. § 9:3-41(a) (West Supp. 1991). An unusual developmental history can provide important diagnostic information for a myriad of neurological and sensory deficit problems. See generally Laxova, *supra* note 270, at 77-78 (listing exposure to teratogens and mutagens and other prenatal and postnatal factors as diagnostic indicators).

281. See TEX. FAM. CODE ANN. § 16.032(b); WASH. REV. CODE ANN. § 26.33.350(2)(a).

282. See *supra* notes 83, 104-18 and accompanying text.

283. TEX. FAM. CODE ANN. § 16.032(e)(10).

284. For a discussion of relevant assistance programs, see *supra* notes 158-64 and accompanying text.

285. See ALA. CODE § 26-10A-19 (Supp. 1991); ALASKA STAT. § 18.50.510 (1991); ARIZ. REV. STAT. ANN. § 8-129 (1989); ARK. CODE ANN. §§ 9-9-505, -506 (Michie 1991); CAL. CIV. CODE § 224.70(a) (West Supp. 1991); CONN. GEN. STAT. ANN. § 45a-746 (West Supp. 1991); FLA. STAT. ANN. § 63.162 (West Supp. 1991); GA. CODE ANN. §§ 19-8-20, -23 (Michie 1991); HAW. REV. STAT. § 578-14.5 (Supp. 1990); ILL. ANN. STAT. ch. 40, para. 1522.4 (Smith-Hurd Supp. 1991); IND. CODE ANN. §§ 31-3-4-25, -26 (Burns 1987 & Supp. 1991); IOWA CODE ANN. § 600.8 (West Supp. 1991); KAN. STAT. ANN. § 59-2130 (Supp. 1990); KY. REV. STAT. ANN. § 199.520 (Michie/Bobbs-Merrill 1991); LA. REV. STAT. ANN. § 9:422.13 (West 1991); MD. FAM. LAW CODE ANN. § 5-328 (Supp. 1991); MASS. ANN. LAWS ch. 210,



parents is, of course, extremely important. One expert estimates that "approximately three-fourths of the information a physician seeks in evaluating the health of a baby involves medical history,"<sup>286</sup> of which the parents' history is an important component. Especially vital is information on maternal disease, particularly during pregnancy, that can affect the health of the child.<sup>287</sup>

The statutes should also require collection and disclosure of the medical history of extended family members and should refer specifically to genetic diseases or disorders as a topic to be covered. Currently, fewer than half the states mandate collection and disclosure of the medical history of other biological relatives, such as siblings or grandparents,<sup>288</sup> and fewer than twenty actually specify that "genetic" history or information is to be included.<sup>289</sup> This information is vital to accurate diagnosis and

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§ 5A (Law. Co-op. 1981); MICH. COMP. LAWS ANN. § 710.27 (West Supp. 1991); MINN. STAT. ANN. §§ 259.46-49 (West 1982 & Supp. 1992); MO. ANN. STAT. § 453.121 (Vernon Supp. 1991); MONT. CODE ANN. § 40-8-122 (1991); NEB. REV. STAT. § 43-107 (Supp. 1990); N.H. REV. STAT. ANN. § 170-B:19 (1990 & Supp. 1991); N.J. STAT. ANN. § 9:3-41.1 (West Supp. 1991); N.M. STAT. ANN. § 40-7-53 (Michie 1989); N.Y. SOC. SERV. LAW § 373-a (McKinney Supp. 1991); N.C. GEN. STAT. § 48-25 (1991); OHIO REV. CODE ANN. § 3107.12 (Anderson 1989); OKLA. STAT. ANN. tit. 10, § 60.5A (West Supp. 1992); OR. REV. STAT. § 109.342(2)(a) (1991) (mother only); PA. STAT. ANN. tit. 23, § 2909 (1991); S.C. CODE ANN. § 20-7-1740 (Law. Co-op. Supp. 1990); S.D. CODIFIED LAWS ANN. § 25-6-15.2 (Supp. 1991); TEX. FAM. CODE ANN. § 16.032 (West Supp. 1991); VT. STAT. ANN. tit. 15, §§ 436(c), 460, 461 (1989 & Supp. 1991); VA. CODE ANN. § 63.1-223 (Michie 1991); WASH. REV. CODE ANN. § 26.33.350 (West Supp. 1991); W. VA. CODE § 48-4-10 (1986 & Supp. 1991); WIS. STAT. ANN. § 48.432 (West Supp. 1991); WYO. STAT. § 1-22-203 (1988 & Supp. 1991).

286. O'Connell, *supra* note 92, at 533 (citing testimony by Professor Stella B. Kontras, M.D., Ohio State University College of Medicine, on Senate Bill 340 (Feb. 22, 1978)).

287. For example, the infants of diabetic mothers may have a particular syndrome called focal femoral hypoplasia, which consists of a cleft palate and very small thigh bones. Laxova, *supra* note 270, at 73.

288. See ALASKA STAT. § 18.50.510 (1991); ARIZ. REV. STAT. ANN. § 8-129 (1989); CONN. GEN. STAT. ANN. § 45a-748 (West Supp. 1991); FLA. STAT. ANN. § 63.162 (West Supp. 1991); HAW. REV. STAT. § 578.14.5 (Supp. 1990); ILL. ANN. STAT. ch. 40, para. 1522.4 (Smith-Hurd Supp. 1991); IOWA CODE ANN. § 600.8 (West Supp. 1991); KY. REV. STAT. ANN. § 199.520 (Michie/Bobbs-Merrill 1991); LA. REV. STAT. ANN. § 9:422.13 (West 1991); MO. ANN. STAT. § 453.121 (Vernon Supp. 1991); NEB. REV. STAT. § 43-107 (Supp. 1990); N.H. REV. STAT. ANN. § 170-B:19 (1990 & Supp. 1991); N.C. GEN. STAT. § 48-25 (1991); OHIO REV. CODE ANN. § 3107.12 (Anderson 1989); OKLA. STAT. ANN. tit. 10, § 60.5A (West Supp. 1992); S.D. CODIFIED LAWS ANN. § 25-6-15.2 (Supp. 1991); TEX. FAM. CODE ANN. § 16.032 (West Supp. 1991); WIS. STAT. ANN. § 48.432 (West Supp. 1991); WYO. STAT. § 1-22-203 (1988 & Supp. 1991).

289. See ARIZ. REV. STAT. ANN. § 8-129 (1989); ARK. CODE ANN. §§ 9-9-505, -506 (Michie 1991); CAL. CIV. CODE § 224.70(b) (West Supp. 1991); GA. CODE ANN. § 19-8-23 (Michie 1991); HAW. REV. STAT. § 578.14.5 (Supp. 1990); IOWA CODE ANN. § 600.8 (West Supp. 1991); KAN. STAT. ANN. § 59-2130 (Supp. 1990); LA. REV. STAT. ANN. § 9:422.13 (West 1991); MINN. STAT. ANN. §§ 259.46-49 (West 1982 & Supp. 1992); N.J. STAT. ANN. § 9:3-41.1 (West Supp. 1991); N.Y. SOC. SERV. LAW § 373-a (McKinney Supp. 1991); OHIO REV. CODE ANN. § 3107.12 (Anderson 1989); OR. REV. STAT. § 109.342(2)(a) (1991); S.C.

treatment of many medical problems<sup>290</sup> that may not be apparent from a history including only medical problems the birth parents have experienced.<sup>291</sup>

Certain other categories of medical history should be identified specifically in the statute. Chief among them is information about any psychological, psychiatric, or substance-abuse problems, evaluations, or treatment, again because this is information the agency might be tempted to omit.<sup>292</sup> It would be useful to mention physical descriptions in the statute, simply because they might otherwise be overlooked. In addition to their importance to the adopted child's building a sense of identity,<sup>293</sup> unusual physical features can often be important diagnostic clues.<sup>294</sup> Requiring information on the identity of providers of medical care to the natural parents,<sup>295</sup> such as physicians, clinics, hospitals, or psychologists, might be extremely useful for unforeseen future emergencies during which the biological parents cannot be found. In such circumstances critical information might be sought directly from the medical personnel by court order.<sup>296</sup> While the laundry list of diseases about which inquiry

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CODE ANN. § 20-7-1740 (Law. Co-op. Supp. 1990); TEX. FAM. CODE ANN. § 16.032 (West Supp. 1991); UTAH CODE ANN. §§ 78-30-16, -17 (1987); WIS. STAT. ANN. § 48.432 (West Supp. 1991). Approximately two-fifths of the states require neither the medical history of biological relatives nor "genetic" information.

290. See Black, *supra* note 85, at 176-78; O'Connell, *supra* note 92, at 533-34. Following a study of the problems encountered by adopted persons who seek access to their medical and genetic history, the American Society of Human Genetics (ASHG) recently endorsed a statement declaring that genetic history should be included in an adoptee's medical files as "a routine part of the adoption process" and that "every person should have the right to gain access to his or her medical record, including genetic data." American Soc'y of Human Genetics, *American Society of Human Genetics Social Issues Committee Report on Genetics and Adoption: Points to Consider*, 48 AM. J. HUM. GENETICS 1009, 1009-10 (1991) [hereinafter *ASHG Report*].

291. As mentioned previously, many genetic conditions skip generations. See Reiser, *supra* note 239, at 65-66. Predictive testing for other genetic conditions may require information about many family members. See Chapman, *supra* note 245, at 1. Beyond the relatively infrequent genetic conditions discussed in the above articles, such as Huntington's Disease and myotonic dystrophy, information on such common diseases as cancer and heart disease, given their tendency to occur in a given biological family, is most useful for health planning and diagnosis. Knowledge of a history of breast cancer, for example, forewarns a woman to be especially alert to danger signals that might otherwise be overlooked.

292. See *supra* notes 81-83, 104-05, 182-97 and accompanying text; see also TEX. FAM. CODE ANN. § 16.032 (West Supp. 1991) ("any psychological, psychiatric, or social evaluations, including the date of any such evaluation, any diagnosis, and a summary of any findings").

293. See *supra* note 130 and accompanying text.

294. Hadley & Petterson, *supra* note 270, at 104. For example, extremely short or tall height "commonly occurs in many genetic, chromosomal, or inherited disorders." *Id.*

295. See IDAHO CODE § 16-1506 (Supp. 1991).

296. For a discussion of the advantages and disadvantages of statutes requiring disclosure

should be made is far too cumbersome to list in a statute,<sup>297</sup> states may wish to consider specific reference to certain conditions, such as venereal disease<sup>298</sup> or maternal AIDS,<sup>299</sup> that are particularly critical. If the statute does not do so, the regulations or forms prepared and distributed to implement the statute clearly should request information regarding the age at and cause of death of family members.<sup>300</sup>

### 3. Social and Educational History of the Child

Because many of today's adoptions are of older children,<sup>301</sup> it is tremendously important for collection and disclosure statutes to include information on the social and educational history of the child. Few states currently address this category of information,<sup>302</sup> despite its effect on the child's future development.

The social history<sup>303</sup> of the child should include information on the child's pre-adoption relationships with parents, siblings, and extended

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of parental medical history by medical personnel, see *infra* notes 363-66 and accompanying text.

297. For example, the Wisconsin Family History Questionnaire lists 58 specific conditions about which it seeks information on the adoptee's parents, full and half-siblings, grandparents, aunts, uncles, and cousins. See Wisconsin Medical/Genetic Form, *supra* note 268.

298. See OKLA. STAT. ANN. tit. 10, § 60.5A (West Supp. 1992).

299. See *infra* notes 375-93 and accompanying text.

300. See Hadley & Petterson, *supra* note 270, at 106. This information is useful to help identify diseases or conditions to which the child might be more susceptible because of their occurrence in the family.

301. See BARTH & BERRY, *supra* note 11, at 8. The authors define older-child adoption as adoption of children age three or older. *Id.*

302. Only 10 states currently specify that the social history of the child should be collected and disclosed. See CAL. CIV. CODE § 224.70(a) (West Supp. 1991); FLA. STAT. ANN. § 63.162 (West Supp. 1991); KAN. STAT. ANN. § 59-2130 (Supp. 1990); MASS. ANN. LAWS ch. 210, § 5A (Law. Co-op. 1981 & Supp. 1991); MINN. STAT. ANN. §§ 259.47-.49 (West 1982 & Supp. 1992); TENN. CODE ANN. §§ 36-1-114, -131 (1991); TEX. FAM. CODE ANN. § 16.032 (West Supp. 1991); UTAH CODE ANN. § 78-30-17 (1987); WASH. REV. CODE ANN. § 26.33.350 (West Supp. 1991); WIS. STAT. ANN. § 48.432 (West Supp. 1991). Several others focus on certain aspects. See ALA. CODE § 26-10A-31 (Supp. 1991) (circumstances under which child is placed, pre-adoption sibling relationships, care prior to adoption by others); N.J. STAT. ANN. § 9:3-41.1 (West Supp. 1991) (child's personality, temperament, and development); N.M. STAT. ANN. § 40-7-53 (Michie 1989) (length of time in care of persons other than petitioner).

Only three state statutes specifically require the collection and disclosure of educational history. See CAL. CIV. CODE § 224.70(a) (West Supp. 1991); MASS. ANN. LAWS ch. 210, § 5A (Law. Co-op. 1981); TEX. FAM. CODE ANN. § 16.032 (West Supp. 1991).

303. Because the information described in this category as social history is critically tied to the adoptee's emotional well-being, it is logical to include it as health-related information that should be disclosed. See *supra* notes 130-31 and accompanying text.

family.<sup>304</sup> To better accommodate a child's adjustment into a new family, it is important for the adoptive parents to be knowledgeable about previous relationships that were important to the child. The child may need support through a grieving process if termination has disrupted relationships the child perceived as positive.<sup>305</sup> Moreover, as an adult, the adoptee may desire information on siblings and other biological relatives to help him or her develop a sense of identity. Social history also should include the nature (relative, foster care, institutional, group care, or adoptive placement) and length of time the child was in the care or custody of someone other than the biological parents or the current adoptive placement, and what is known about the child's relationship with these caregivers.<sup>306</sup> Information on the child's personality, temperament, and behavior must be included.<sup>307</sup> The circumstances under which the child was placed for adoption should also be disclosed.<sup>308</sup> The adoptive parents must be able to respond, at the appropriate time, to the child's questions about why the child was adopted.<sup>309</sup> It is also extremely important that the statutes specify that any history of physical, sexual, or emotional

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304. See ALA. CODE § 26-10A-31(d)(9) (Supp. 1991); TEX. FAM. CODE ANN. § 16.032(c) (West Supp. 1991).

305. In one family, known to the author, an adoptive mother was concerned about her eight-year-old son's adjustment to placement in her home. After a month with her, he revealed he had two siblings still in foster care about whom the mother had never been told. She subsequently adopted both siblings so the children could be together.

306. See ALA. CODE § 26-1-A-31(g)(5) (Supp. 1991); N.M. STAT. ANN. § 40-7-53(D)(5) (Michie 1989). The number of placements a child has been through, particularly disrupted adoptive placements, may greatly affect a child's ability to adjust in a new adoptive placement. Studies on adoption disruption indicate characteristics of multiple pre-adoptive placements and previous adoptive placements contribute to adoption instability. BARTH & BERRY, *supra* note 11, at 72. Sometimes former foster parents can be of great assistance to adoptive parents. In one instance a foster mother was a significant asset to a single adoptive father of an eight-year-old boy with a history of sexual abuse, emotional problems, and self-mutilation as part of satanic worship. *Id.* at 49, 176.

307. See N.J. STAT. ANN. § 9:3-41.1 (West Supp. 1991). One of the stressors that may lead to maladaptive coping on the part of the adoptive parent is the lack of everyday information concerning the child's behavior. For example, a new adoptive mother has no background to assess whether her child's lying is "just a temporary lapse in honesty or an indication of a deeply ingrained habit." BARTH & BERRY, *supra* note 11, at 56. Older children may come to an adoptive placement with seriously disturbed behavioral patterns—stealing, destruction of property, mutilation of self or animals, or sexual or violent attacks on siblings or adoptive parents. *Id.* at 175; see *supra* notes 104-05 and accompanying text. Experts have observed that adoptive families handle these behavioral problems better if they are prepared. "The greater the surprises, the greater the difficulty." BARTH & BERRY, *supra* note 11, at 175.

308. Several studies have shown that adoptive placements following contested parental-rights termination are at higher risk for disruption. BARTH & BERRY, *supra* note 11, at 73.

309. Failure to provide an adopted child with honest answers to such questions can be psychologically damaging. SOROSKY et al., *supra* note 77, at 91-94; McInturf, *supra* note 116, at 376; Burke, *supra* note 43, at 1201-04.

abuse be included in the information to be disclosed.<sup>310</sup> This information is critical to ensuring that a child receives proper diagnosis and treatment if mental, emotional, or special behavioral problems develop after placement.<sup>311</sup>

A child's educational history should include information about the child's enrollment and performance in schools the child has attended, the results of any psychometric or other educational or standardized testing, and information about any learning disabilities or other special education needs the child may have.<sup>312</sup> This information is essential to place the child in a proper educational setting after placement in the adoptive home, to assess the child's needs adequately, and to facilitate intellectual and social growth and development.

#### 4. Social History of Biological Parents and Ancestors

To give birth is to establish the hereditary link. It forces you to think back about your own heritage—to think of the traits and talents, the shapes and sizes of ancestors whose genes you carry. The adoptee goes back only into himself. Beyond that there is a wall. And it is the fear of what is behind that wall—magnified a thousand rational and irrational times in one's imagination—that causes all the mischief.<sup>313</sup>

Although transmitting social background information on the biological parents and other extended relatives may seem to be unrelated to and comparatively less important than other medical history and the child's social history, it is tremendously important in fostering the adoptee's sense of identity, which is critical to healthy emotional development.<sup>314</sup>

This social background information should include information about the racial, national, and ethnic origin of the adoptee's ancestors. This information is important to the adoptee both for psychological reasons and because it has value for diagnosing genetically-inherited diseases that occur frequently in certain ethnic or racial groups.<sup>315</sup>

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310. See TEX. FAM. CODE ANN. § 16.032(a) (West Supp. 1991). Prior to enactment of the abuse-disclosure provision, many families who adopted in Texas were denied information about previous physical or sexual abuse experienced by their children, which delayed proper treatment for their subsequent emotional problems and contributed to years of severely disturbed behavior. Belkin, *supra* note 2, at B8; see also BARTH & BERRY, *supra* note 11, at 15 (reporting that a child's history of abuse is critical to pre-adoption assessment).

311. See *supra* notes 114-18 and accompanying text.

312. See TEX. FAM. CODE ANN. § 16.032(d) (West Supp. 1991).

313. FISHER, *supra* note 233, at 52.

314. Black, *supra* note 85, at 203-05; Whitehouse, *supra* note 3, at 20; see *supra* notes 130-31 and accompanying text.

315. Hadley & Petterson, *supra* note 270, at 103. For example, Tay Sachs disease is preva-

Information about tribal membership of ancestors should be required so that adoptees as adults can seek the benefits of tribal membership.<sup>316</sup> Information regarding the parents' age at the time of the birth of the adoptee, their religion, their educational background, their employment history, talents, hobbies, and special interests all should be provided to the adoptive parents, so that they can share this information with their adopted children at appropriate times to help them resolve issues regarding their adoption and who they are,<sup>317</sup> and to adoptees themselves upon reaching adulthood. Information about whether the biological parents are related to each other should also be disclosed. Children of incestuous relationships have a significantly increased risk for severe mental retardation and other genetic conditions.<sup>318</sup> States might also consider allowing the collection and disclosure process to transmit other nonidentifying information that the biological parents voluntarily provide, such as photographs or a letter to the child, with the intent that it be shared with the child.<sup>319</sup>

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lent among those of Jewish ancestry, sickle cell anemia is most common among African-Americans, cystic fibrosis is most common among Caucasians, and spina bifida more frequently strikes those of Irish descent. *Id.*

316. See ALASKA STAT. § 18.50.510(a)(2)(C) (1991).

317. See Kitzman, *supra* note 99, at 23 (adoptive mother describing her children's delight upon learning their interests and hobbies were similar to those of their birth parents); see also *supra* note 130 and sources cited therein (discussing the importance of background information to the adoptee's sense of identity).

Several states require collection of this type of information. See ALASKA STAT. § 18.50.510 (1991); CONN. GEN. STAT. ANN. § 47a-746 (West Supp. 1991); ILL. ANN. STAT. ch. 40, para. 1522.4 (Smith-Hurd Supp. 1991); N.M. STAT. ANN. § 40-7-53(D) (Michie 1989); OHIO REV. CODE ANN. § 3107.12(D)(3) (Anderson 1989); S.D. CODIFIED LAWS ANN. § 25-6-15.2 (Supp. 1991); VT. STAT. ANN. tit. 15, § 436(c) (1989).

318. Black, *supra* note 85, at 194-95. Black reports a study conducted by Bunday which found that in children of first-degree relatives (parent and child or siblings), the risk of severe mental retardation was one in four, the risk of an autosomal recessive disease, a generation skipping genetic disorder (such as Tay Sachs, sickle cell anemia, or cystic fibrosis) was one in seven, and the risk of polygenetic malformation was one in eight. In Bunday's study of 215 such children followed into adolescence, fewer than half were normal. *Id.* at 194. The risk of such genetic disorders and mental retardation among offspring of second-degree relatives (uncle/niece, for example) or first cousins was less, but still much higher than in the general population. *Id.* at 194-95; see also Lamport, *supra* note 4, at 114 (relating that because incest often is not revealed, clinicians have developed a standard set of criteria for evaluating children of suspected incest).

In *M.H. v. Caritas*, 475 N.W.2d 94 (Minn. Ct. App. 1991), adoptive parents sued an adoption agency for its failure to advise them that their son was conceived in an incestuous relationship between siblings. *Id.* at 97. The child had serious emotional problems and was diagnosed with attention deficit hyperactivity disorder. *Id.* The appellate court recognized these allegations as sufficient to sustain claims for intentional and negligent misrepresentation, and reversed a summary judgment for defendants. *Id.* at 97-99.

319. See ALASKA STAT. § 18.50.510(a)(9) (1991) (allowing state registrar to release to adoptive parents or adult adoptees "information provided by the biological parent for disclo-

### 5. Identifying Information

Every state with a statute allowing disclosure of medical and social history specifies that the disclosure include only "nonidentifying information."<sup>320</sup> Frequently states have developed separate disclosure mechanisms that allow adult adoptees to obtain the identity of their biological parents,<sup>321</sup> normally requiring consent or at least a lack of objection by the biological parent.<sup>322</sup> The pros and cons of allowing adult adoptees an absolute right to discover the identity and location of their biological parents have been extremely controversial in recent years,<sup>323</sup> and extensive discussion of this subject is beyond the scope of this Article. It is of note that one of the arguments favoring disclosure is that allowing adult adoptees potential access to biological relatives fosters communication of health information that might not otherwise have been disclosed.<sup>324</sup> Many advocates of disclosure contend that this information is crucial to an adult adoptee's psychological well-being.<sup>325</sup> In any event, it is important for the state to maintain a system for acquiring and recording current names and addresses of both adoptees and biological relatives, so that each could be located, by court order, if further information or even participation in medical treatment is necessary to preserve the health of either the adoptee or the biological relative.<sup>326</sup>

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sure to the child, which may include such items as photographs, letters, and a statement explaining the reasons for the adoption").

320. See, e.g., ARIZ. REV. STAT. ANN. § 8-129(A) (1989); ARK. CODE ANN. § 9-9-505(a) (Michie 1991); GA. CODE ANN. § 19-8-23(f)(2) (Michie 1991).

321. Section 18.50.500(a) of the Alaska Statutes requires the state to disclose to an adopted person who is 18 or older an uncertified copy of his birth certificate, without obtaining the consent of the biological parent. ALASKA STAT. § 18.50.500(a) (1991). In addition, any information on the current name or address of the biological parent that has been voluntarily supplied will also be disclosed. *Id.* The state will disclose the name and address of the adoptee to the biological parent upon written request by the adoptee. *Id.*

322. See, e.g., GA. CODE ANN. § 19-8-23(f)(3)(A) (Michie 1991); MICH. COMP. LAWS ANN. § 710.68a (West, Supp. 1991); OHIO REV. CODE ANN. § 3107.40 (Anderson 1989); see also *supra* notes 95-96 (discussing mutual-consent registries and search-and-consent statutes).

323. See, e.g., FISHER, *supra* note 233; Sweeney, *supra* note 130, at 343-69; Burke, *supra* note 43; Gloor, *supra* note 43; Prager & Rothstein, *supra* note 43; Tartanella, *supra* note 43.

324. See generally Whitehouse, *supra* note 3, at 19-20 (biopsy patient obtained information that lumps, but not breast cancer, were common in her family).

325. See *Backes v. Catholic Family & Community Servs.*, 210 N.J. Super. 186, 193, 509 A.2d 283, 286-87 (Super. Ct. Ch. Div. 1985); *Mills v. Atlantic City Dep't of Vital Statistics*, 148 N.J. Super. 302, 318-19, 372 A.2d 646, 655 (Super. Ct. Ch. Div. 1977); Burke, *supra* note 43, at 1202-04; Prager & Rothstein, *supra* note 43, at 139-40.

326. For example, Iowa provides that the court may open adoption or termination records if necessary to prevent irreparable physical harm to an adopted person or the person's offspring. IOWA CODE ANN. § 600.16 (West 1981 & Supp. 1991). The law also permits, where necessary, revelation of the identity of the natural parents to medical personnel, who must try not to reveal the identity to the adoptee. *Id.* Delaware allows the release of identifying infor-

*E. Privacy, Efficacy, and Other Concerns Related to the Methods for Collection, Retention, and Disclosure of Information*

1. Responsibility for Collection

Current statutes vary widely on the question of who is ultimately responsible for collecting medical and social history. Many states place this duty on the state department that handles adoptions, the private agency making the placement,<sup>327</sup> or some other intermediary who places the child.<sup>328</sup> Some states place the burden on the court,<sup>329</sup> others on the petitioner for adoption,<sup>330</sup> the parent who surrenders the child for adoption,<sup>331</sup> or the state or agency designee who does the investigation.<sup>332</sup> One state simply requires the adoptive parents to submit a doctor's certificate showing the physical and mental condition of the child.<sup>333</sup>

If a public or private agency is handling an adoption, that agency should be required by statute to collect the information described in the previous section. Adoption agencies are licensed by the state and subject to state regulation,<sup>334</sup> and it would be easy to provide uniform training to their personnel in the procedure and skills necessary to collect and transcribe relevant data properly, and prepare the necessary reports.<sup>335</sup> Since

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mation by court order when it is needed for the health of an adopted individual or blood relative, and allows the disclosure of the location and identification of siblings if siblings are needed to participate in any medical treatment. DEL. CODE ANN. tit. 13, § 924 (Supp. 1990).

327. See, e.g., CONN. GEN. STAT. ANN. § 45a-748 (West Supp. 1991); KY. REV. STAT. ANN. § 199.520 (Michie/Bobbs-Merrill 1991); N.C. GEN. STAT. § 48-25 (1991).

328. See, e.g., ALASKA STAT. § 25.23.185 (1991); ARIZ. REV. STAT. ANN. § 8-129 (1989); ARK. CODE ANN. § 9-9-505 (Michie 1991).

329. See, e.g., MICH. COMP. LAWS ANN. § 710.27 (West Supp. 1991); OR. REV. STAT. § 109.342 (1991).

330. See, e.g., KAN. STAT. ANN. § 59-2128 (Supp. 1990); UTAH CODE ANN. § 78-30-17 (1987).

331. See, e.g., LA. REV. STAT. ANN. § 9:422.13 (West 1991); VT. STAT. ANN. tit. 15, § 436 (1989).

332. See, e.g., ALA. CODE § 26-10A-19 (Supp. 1991); FLA. STAT. ANN. § 63.162 (West Supp. 1991).

333. MISS. CODE ANN. § 93-17-3 (Supp. 1988).

334. "Every state has some procedure for the licensing of adoption agencies." ADOPTION LAW AND PRACTICE, *supra* note 76, § 3.03[2].

335. A survey of social workers from public adoption agencies in all 50 states has indicated strong recognition of a great need for genetic education programs appropriate for the staff of adoption agencies. Plumridge et al., *supra* note 126, at 213. Another expert, reflecting on the implication of "wrongful adoption" litigation, observed that all adoption agency employees who are responsible for placement in a direct or supervisory capacity must receive "routine instruction through staff development programs and in written policy guidelines on the importance of" disclosure and appropriate disclosure procedure. Carol Amadio, *Wrongful Adoption—A New Basis for Litigation: Another Challenge for Child Welfare*, J.L. & SOC. WORK, March 1989, at 23, 30; see also Belkin, *supra* note 2, at A1, B8 (explaining that many social workers do not understand the need for pre-adoption information).



these agencies often are affiliated with national or regional social work organizations, they are also the group most readily accessible for updating training and implementing procedural changes. Moreover, their professional personnel, who should be the ones actually collecting the data, are already trained to deal with difficult interpersonal situations<sup>336</sup>—unlike court employees, for example, whose training may be more clerical in nature.

If an agency is not involved in the adoption, the ultimate responsibility for ensuring that necessary information is collected should be placed upon the attorney who is serving as intermediary or representing the petitioners for adoption.<sup>337</sup> The attorney is licensed by the state and therefore subject to discipline, and is also part of a training network through continuing legal education. Limitations should be placed upon the attorney's ability to delegate the collection responsibility if the attorney does not herself collect the information and prepare the report. Contracting with a licensed social worker, training a paralegal in the attorney's office, or allowing the information to be collected by a professional in the obstetrician's office, if the birth mother's contact is directly with the obstetrician, might all be acceptable options. Although it would be tempting to require that only a licensed social worker perform the task, such a limitation might unnecessarily deter adoptive placements. Many birth mothers choose to place their babies through independent adoption rather than through an agency because they prefer to deal only with a lawyer or doctor, a relationship they may perceive as more personal and confidential.<sup>338</sup>

## 2. The Extent of the Duty to Investigate and the Duty to Provide Information

Most disclosure statutes offer little guidance regarding the extent of the investigation that must be performed or the responsibility to provide information to the intermediary charged with gathering the information. Several statutes require collection or disclosure of "available" or "reasonably available" information.<sup>339</sup> A few states specifically require a parent

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336. See Plumridge et al., *supra* note 126, at 213 (collecting genetic information "is a refinement of already existing social work skills and can be enhanced through specialized training").

337. See Gustafson, *supra* note 185, at 857.

338. Linda J. Davie, Note, *Babes and Barristers: Legal Ethics and Lawyer-Facilitated Independent Adoptions*, 12 HOFSTRA L. REV. 933, 973 (1984).

339. See, e.g., ARIZ. REV. STAT. ANN. § 8-129(A) (1989) ("reasonably available"); IDAHO CODE § 16-1506 (Supp. 1991) ("reasonably known or available"); N.J. STAT. ANN. § 9:3-41.1 (West Supp. 1991) ("available"); N.Y. SOC. SERV. LAW § 373-a (McKinney Supp. 1991) ("available"); WYO. STAT. § 1-22-116 (Supp. 1991) ("available").

who relinquishes a child for adoption to provide medical or other background information.<sup>340</sup> One state requires that any person who has relevant background information about a child to be adopted "shall, upon request" cooperate with the investigator and disclose the information, "whether contained in sealed records or not."<sup>341</sup> This relatively cursory treatment belies the complexity of the issues related to the parameters of appropriate investigation, and the extent to which disclosure should be pursued or compelled.

a. Reasonable Efforts Requirement—Obtaining Information Through Voluntary Cooperation of Parents or Other Guardians

The agency or other intermediary<sup>342</sup> who places a child for adoption should be required by statute to make reasonable efforts<sup>343</sup> to obtain all of the medical and social information described in Part III(D)<sup>344</sup> of this Article. Describing the duty as one to make "reasonable efforts" to obtain information, rather than a duty to collect and disclose "available" information, better conveys the agency's or intermediary's responsibility to seek out the required information actively as opposed to passively recording whatever information is offered. While an all-inclusive description of "reasonable efforts" cannot be achieved,<sup>345</sup> the statute or state regulations implementing the statute should offer guidance regarding the essential steps. Obtaining all information available from the parent(s) or other legal guardian who relinquishes a child for adoption should always

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340. FLA. STAT. ANN. § 63.082 (West 1985); LA. REV. STAT. ANN. § 9:422.13(A) (West 1991).

341. IOWA CODE ANN. § 600.8(4) (West 1981).

342. See *supra* notes 334-38 and accompanying text.

343. See CONN. GEN. STAT. ANN. § 45a-748 (West Supp. 1991). Hawaii's statute provides that:

[a]ll affected public agencies and all child-placing organizations . . . shall make reasonable efforts to complete this form with medical information on both natural parents, to obtain from the natural parents written consent to the release of this information to or for the benefit of the adopted child, and whenever possible, to obtain from the natural mother a signed release to receive a copy of all of her medical records, relating to the birth of the adopted child, which are within the possession of the hospital or other facility at which the child was born.

HAW. REV. STAT. § 578-14.5(b) (Supp. 1990).

344. See *supra* notes 263-326 and accompanying text.

345. What is reasonable in every conceivable circumstance obviously cannot be statutorily regulated in detail. Nevertheless, requiring reasonable efforts affirms the agency's or intermediary's statutory duty to investigate to the extent reasonable under the circumstances, mirroring the "reasonable person standard" used in determining negligence on a case by case basis. See generally KEETON et al., *supra* note 34, § 32 (discussing reasonable person standard for negligence).

be required.<sup>346</sup> If the child has been in the physical custody of someone other than the relinquishing parent(s) (such as grandparents or foster care) for any significant period of time, those caretakers should also be interviewed.<sup>347</sup> "Reasonable efforts" should also include requesting a release from the relinquishing parent or other legal custodian and obtaining a copy of *all* of the child's medical records.<sup>348</sup>

Efforts must also be made to interview parents who are not voluntarily relinquishing a child, although special considerations may dictate the timing and circumstances of the contact. The issue of interviewing the birth father of a child born out of wedlock is particularly difficult. Often, an expectant mother who contacts an adoption agency or intermediary is strongly opposed to any contact with the child's biological father.<sup>349</sup> A requirement that contact be made prior to birth or earlier than is otherwise necessary may prompt mothers to choose another option, such as abortion or black-market adoption. Both birth mothers and prospective adoptive parents may fear that an inquiry of this type, which emphasizes the genetic link, may prompt a father to appear and oppose an adoption that he might otherwise have ignored. Viewing this dilemma from the perspective of the best interests of the child, it is extremely difficult to quantify the risks each alternative creates. Delaying the inquiry until after the adoption is final may result in prospective adoptive parents or social workers lacking medical information that could alter their decision and result in an inappropriate or unhappy placement for the child. Some necessary medical treatment could be delayed, for finalizing an adoption can sometimes take more than a year. More probable is that the delay could decrease the possibility that the father can be located. Even if inquiry is delayed only until the point at which the father's right to contest the adoption is foreclosed, in rare instances some critical newly-un-

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346. See OHIO REV. CODE ANN. § 3107.12 (Anderson 1989) for an example of a detailed statute describing the manner in which an investigation to obtain medical and social history should be conducted.

347. It is important to obtain this information from the actual caregivers who would be most familiar with any medical problems or special needs the child has exhibited, regardless of whether that caregiver had legal custody. For an illustration of the kind of tragedy that may result when an agency fails to relay to adoptive parents information recorded by foster parents, see Jacob, *supra* note 109, at 48 (asserting that failure to relay information indicating fetal alcohol syndrome resulted in years of ineffective therapy and upheaval for family).

348. To the extent these records can be located, a child should enter an adoption with the same access to his own medical records that an unadopted child would have. In addition to retaining a copy of these records in a permanent file, a copy should be provided to the adoptive parents, with identifying information redacted, so that the child's postadoption medical or psychiatric health-care providers will have access to necessary history.

349. Not infrequently, a mother who has consented to the adoption of her infant will assert she does not know who the father is, or does not know his whereabouts, to avoid involving him in the adoption process. See Johnson, *supra* note 16, at 36.

earthed information might cause a placement to be disrupted, or the child could be forced to remain in foster care longer than is desirable. On the other hand, increasing the incidence of contested adoptions does not serve the child's best interests, nor would awarding custody to a father who, upon receiving notice, would not otherwise have been motivated to contest.

These conflicting considerations cannot be totally reconciled. Ultimately, constitutional<sup>350</sup> and state statutory requirements<sup>351</sup> usually necessitate giving fathers of both infants and older children notice and the opportunity to appear prior to finalizing an adoption. Mandating that efforts be made to obtain the required information from the father at or shortly after the time notice is given should not additionally deter birth mothers from legal adoption. In many states the majority of fathers entitled to notice already have some relationship or have taken steps to establish a relationship with the child, and their decisions are unlikely to be affected by the medical inquiry.<sup>352</sup> Even in states that require notice to

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350. The United States Supreme Court has unanimously held that the Due Process Clause requires that notice of adoption proceedings be given to the father of a child born in wedlock. *Armstrong v. Manzo*, 380 U.S. 545, 550, 552 (1965).

The Supreme Court has also acknowledged that if a father of a child born out of wedlock has developed a relationship with his biological child and accepted "some measure of responsibility for the child's future," his parental rights cannot be terminated in an adoption without notice and an opportunity to be heard. *Lehr v. Robertson*, 463 U.S. 248, 261-62 (1983). By contrast, the *Lehr* Court determined that a father who has never had any significant custodial, personal, or financial relationship with a child (and in fact failed to attempt to establish paternity until the child was over two) was not entitled to notice of adoption proceedings. *Id.* at 262; see also *Michael H. v. Gerald D.*, 491 U.S. 110, 123, 130 (1989) (plurality opinion) (four justices expressing willingness to narrow due process rights of biological father further if the parental relationship did not develop within traditional unitary family).

The Supreme Court has not yet addressed the issue of the constitutional rights of putative fathers of children who are adopted as young infants.

351. See generally ADOPTION LAW AND PRACTICE, *supra* note 76, §§ 4.10[1], 2.04[2] (discussing adoption procedures at length and detailing the problems of notice to unwed fathers).

The Uniform Putative and Unknown Fathers Act requires that notice of adoption proceedings be given to all putative fathers known to the person seeking termination in adoption proceedings. UNIF. PUTATIVE & UNKNOWN FATHERS ACT § 3, 9B U.L.A. 33-34 (Supp. 1991). A putative father, with certain exclusions, includes any man who claims to be, or is named as the biological father or possible biological father of a child, and whose paternity has not yet been adjudicated. *Id.* § 1, 9B U.L.A. 30.

352. See, e.g., N.Y. DOM. REL. LAW § 111 (McKinney 1988). The statute provides that a father of a child born out of wedlock must consent before adoption occurs if he has supported, visited, or communicated regularly with a child placed for adoption more than six months after birth, or, for a child placed younger than six months of age, if he lived with the mother for six months preceding placement, held himself out as the father, and paid pregnancy or birth-related expenses. *Id.* Section 111(a) provides that, in addition to the above fathers entitled to withhold consent, other fathers are entitled to notice of the adoption, including those who have been adjudicated to be the father, those who have filed an unrevoked notice of intent to claim paternity or an instrument acknowledging paternity, those recorded on the child's

fathers who have not made previous efforts to establish a relationship with the child,<sup>353</sup> the risk that medical inquiry would influence a father who is already entitled to notice is minimal and should not outweigh the importance of the information to be gathered. If such a state's legislature determines that the risk of creating contested adoptions is substantial, however, it could choose to leave the timing of the inquiry to the discretion of the agency or intermediary, provided that inquiry is made shortly after a court determines the adoption can proceed without the father's consent.

In states such as New York that do not require notice to all fathers,<sup>354</sup> the risk of medical inquiry prompting challenges from fathers who would not otherwise receive notice at all is magnified. An inquiry prior to termination of their parental rights would, of course, provide de facto notice of the adoption proceedings. The corresponding concern that the birth mothers would be harassed or seek an alternative to legal adoption is also heightened. Many states may conclude that these risks do not outweigh the importance of seeking medical information from the father early in the adoption process.<sup>355</sup> States that have determined that notice creates an undue risk of harassment for the mother or adverse consequences for the child, however, could still mandate that efforts to obtain this information occur after the father's parental rights have been terminated in the adoption proceeding.

In addition to biological fathers of infants, reasonable efforts must also be made to collect information from any other parents whose rights have been involuntarily terminated prior to an adoption. This information is especially crucial because these children have normally been in the custody of at least one parent for a significant period of time. Incorporating such an inquiry into the early stages of state-initiated dependency or neglect proceedings in which children are removed from a parent's custody might help ensure that the necessary information is available in cases that do proceed to termination and subsequent adoption.<sup>356</sup>

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birth certificate, those living with the child and the child's mother and holding themselves out as the father, those identified as the father by the mother in a sworn statement, and former husbands of the mother married to her within six months of the child's birth. *Id.* § 111(a).

353. See OKLA. STAT. ANN. tit. 10, § 60.7 (West Supp. 1992).

354. N.Y. DOM. REL. LAW § 111 (McKinney 1988).

355. This conclusion undoubtedly is influenced by the author's belief that all putative fathers, as a matter of constitutional right and public policy, should be entitled to notice of adoption proceedings.

356. Social workers are taught that the best time to get information may be upon initial contact with the agency, when a parent often depends upon the agency for a service or a favorable report, or at the time of initial contact with the court system, when the parent's fear of the legal system may motivate cooperation. Diane Knight, *Working with the Resistant or Reticent Client Workshop*, in GENETIC FAMILY HISTORY, *supra* note 1, at 56, 56. While gath-

b. Obtaining Information from Other Sources

When complete information cannot be obtained from these sources, efforts should be made to contact other relatives, medical care providers, and other community resources,<sup>357</sup> to the extent that such contacts can be made without invading the parents' right to privacy. Obtaining medical records or supplemental information regarding *the child's* medical care and educational testing from medical providers or schools should not be problematic. In most cases, a parent or other legal custodian of a child voluntarily relinquished for adoption should voluntarily sign a consent authorizing this disclosure. Children to be adopted following involuntary termination by the state would be in the state's custody, so releases could be signed by the appropriate official. On the rare occasions when such a release could not be obtained, however, the statutes should authorize schools and medical personnel to release such records. The focus of the child's educational or medical records would be information on the child's own medical or educational problems, not the parents', and such information, for the reasons discussed previously, is essential to the care of the child.<sup>358</sup>

Such records could reveal information about a parent's conduct, such as child abuse, that the parent would prefer to shield; a parent's right to privacy in this context, however, should not supersede the child's need for appropriate future treatment and counseling. There is already widespread agreement, as evidenced by the enactment of child abuse reporting laws, that the principles of medical confidentiality<sup>359</sup> and the right to privacy<sup>360</sup> are not inviolate when prevention of harm to an iden-

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ering the history at this stage will necessitate collection of information on many children who will never be adopted, the benefit to those who ultimately are adopted sufficiently offsets this disadvantage.

On the other hand, if states adopt a provision for use immunity for the information provided, care must be taken to delay collection until the prosecutor has gathered the evidence to use in the juvenile proceeding, so that the termination proceeding is not affected by the collection of medical and social history. See *infra* text accompanying note 443.

357. One expert suggests that the following sources be investigated when a biological parent cannot supply all of the necessary information: (1) Adult siblings of the parent; (2) grandparents or other significant relatives; (3) ex-spouses of the parent; (4) adult children of the biological parents; (5) physicians, psychiatrists, psychologists, or other medical personnel who have treated the biological parents, siblings, or the child to be adopted; (6) the local welfare department; (7) school records; (8) a local church, parish, or synagogue; or (9) the local police. Knight, *supra* note 356, at 57.

358. See *supra* notes 114-29 and accompanying text.

359. See *supra* notes 59-64 and accompanying text.

360. See *supra* notes 36-58 and accompanying text.

tifiable third party necessitates disclosure.<sup>361</sup> The same rationale would justify release of information about the medical history of a parent or other family member that might be contained in *the child's* medical records. If such information is contained in the child's records, the recorder considered it relevant to the care or treatment of the child. If it was provided in the context of a confidential communication to the child's physician or school, the purpose of the communication is served by making it available to future health-care providers. Physicians have considerable latitude to make disclosures to family members when the patient's health requires the disclosure, and to discuss confidential information with other health-care professionals directly involved with the treatment of the patient.<sup>362</sup> Acquiring information on family members that is contained in *the child's* medical records for transmission to adoptive parents and future medical caregivers is consistent with these principles.

More difficult questions are raised by statutory authorization for medical personnel to disclose without the patient's consent the medical records of a parent or other biological relative to an adoption agency or other adoption intermediary. Unlike information found in the child's records, this information was not initially disclosed to the medical caregiver for the purpose of treating the adoptee. Instead, the parent or other relative was the patient who established the confidential relationship. Although specific statutory authorization should obviate any tort liability for disclosure in these circumstances,<sup>363</sup> the wisdom of such authorization requires balancing several considerations. First, one of the primary purposes of medical confidentiality is to encourage patients to seek treatment and to provide their physicians full and truthful information.<sup>364</sup> Proliferation of statutory exceptions could inhibit this communication. In addition, numerous exceptions thwart the privacy interests of the patient. Furthermore, this particular exception could persuade a biological mother who was aware of it to choose abortion or black market adoption. Neither of these alternatives is preferable from the viewpoint of the child's best interests, which of course must justify the exception in the first place. On the other hand, certain information, as discussed in previous sections,<sup>365</sup> is vital to appropriate diagnosis and treatment of the

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361. Gauthier, *supra* note 60, at S:352; see ANNAS, *supra* note 40, at 181-82; THOMAS A. SHANNON & JO ANN MANFRA, *LAW AND BIOETHICS* 279 (1982).

362. ANNAS, *supra* note 40, at 185, 187; see Zelin, *supra* note 58, at 711-12.

363. *Boyd v. Wynn*, 286 Ky. 173, 177-78, 150 S.W.2d 648, 650 (1941); see *Horne v. Patton*, 251 A.Ja. 701, 706-07, 287 So. 2d 824, 829 (1974); ANNAS, *supra* note 40, at 181-82; Zelin, *supra* note 58, at 713.

364. Gauthier, *supra* note 60, at S:351.

365. See *supra* notes 114-29 and accompanying text.

child in future years, and to an appropriate placement.

In view of all of these factors, a narrow statutory authorization is warranted. When accurate information cannot be obtained from, or with the permission of, birth parents, the courts should be authorized to order the release of medical information that could have a significant effect on the adoptee's health from records of a birth parent. Such information should include genetic disorders; records of prenatal treatment and care, labor, and delivery; information on maternal disease, substance abuse, or exposure to other high-risk factors during the pregnancy; and information on medical or psychological conditions that have a significantly higher rate of incidence within families where they have occurred previously. The requirement of a court order provides some protection that the request will be limited to matters that could significantly affect the future placement, medical diagnosis, and treatment of the adoptee. Such limited invasion of a parent's privacy interests fits within a well-recognized justification that the invasion is necessary to prevent harm to an identified third party, who in this instance would be the adoptee.<sup>366</sup>

The effect of this limited disclosure exception on the mother's choices remains a serious concern, one that is difficult to quantify compared with the risks posed by no information. Adoption of immunity provisions<sup>367</sup> may diminish the risk that knowledge of an investigator's ability to obtain medical records might coerce a mother otherwise favoring legal adoption to choose another course. Also, the fact that in most states the identity of biological parents may not be revealed without their consent to anyone outside the adoption agency or other intermediary, including the adoptive parents or adoptee,<sup>368</sup> might reassure a parent that the revealed medical information cannot be linked to her.

Moreover, appropriate limitations on the use of the authorization should avert the potential for abuse. The statutory guidelines should direct the courts to order release of a parent's medical records *only* when there is some indication that the information would have a significant effect on the health of the adoptee, and cannot be obtained accurately from or with the consent of the parents or other relatives. Obtaining copies of a parent's medical records thus should not become routine in

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366. See Gauthier, *supra* note 60, at §352. Treatment of the child should also satisfy the "reasonable public interest" standard, which allows various governmental data collection practices to survive constitutional scrutiny and avoid tort liability for invasion of privacy. See *supra* text accompanying notes 70-74.

367. See *infra* notes 432-43 and accompanying text.

368. Only two states, Alaska and Kansas, allow the identity of the biological parents to be released to an adult adoptee without the consent of the biological parents. ALASKA STAT. § 18.50.500 (1991); KAN. STAT. ANN. § 65-2423 (1985); see ADOPTION LAW AND PRACTICE, *supra* note 76, § 13.01[3], at 13-21 (Supp. 1991).



every adoption. Application for such a court order should not take place until after a child has been surrendered for adoption (or termination has otherwise taken place) to avoid unnecessary invasion of parental privacy in cases in which no adoption would ultimately occur. The parent whose records are sought should be notified of the hearing on the application and afforded opportunity for counsel.<sup>369</sup>

Finally, the authorization to compel disclosure should be limited to the parents' records, absent compelling, life-threatening circumstances. If a broader authorization were extended to the records of all biological relatives whose health would be relevant, this would tremendously expand the exception and thus risk eviscerating confidence in medical confidentiality. It seems unfair to allow the invasion of the medical and psychological records of all biological relatives, since such relatives would rarely have had any role in the events that precipitated the adoption, and therefore no control over the subsequent need for disclosure. Moreover, while it seems justifiable to impair the parents' right to privacy to serve their child's interests, given societal recognition of a particular duty on the part of parents to promote the welfare of their children,<sup>370</sup> all biological relatives whose medical status might be relevant bear no similar responsibility. An authorization allowing invasion of their records would be unwarranted. Unlike parents, who in most states wield control over the revelation of their identity to adult adoptees,<sup>371</sup> biological relatives have no similar control. Information of a highly personal nature, such as diagnosis of schizophrenia or other mental illness, alcoholism, or Huntington's Disease, might be conveyed to persons not of the relative's choosing if the adult adoptee, through registries or mutual consent statutes, reunites with the adoptee's birth parents or siblings.<sup>372</sup>

In addition, the existence of some indication that the information

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369. If the child is in the custody of the state at the time the records are sought, the state should pay the attorney's fees for representation of the parent at the hearing on the application. If the child has been relinquished to an agency, the agency should pay these fees and build the cost into its fee structure. In a private adoption, the fees should be paid by the prospective adoptive couple, analogous to the cost for an independent counsel to represent the relinquishing parent in the adoption itself.

370. Parents are legally responsible for the support of their children, *see* CLARK, *supra* note 214, § 6.2, at 259, and they have a duty to provide them with medical and psychiatric care, *id.* § 9.3, at 342-43.

371. *See supra* note 368 and accompanying text.

372. For example, a great-aunt who has been treated for manic depression should not have her records subject to disclosure, even though a history of manic depression in the family would be relevant to the child's history. The risk to the child is not as high as it would be if a parent had the disorder, and the information could be revealed to other family members or friends if the adoptee, as an adult, found his birth family through the registries.

would have a significant effect should be a prerequisite to obtaining the parents' medical records. If that clue exists, it seems less likely that thorough investigation, possibly including interviews of many family members, would not reveal enough information even without the records of other relatives to alert adoptive parents and adoptees to a risk. This may not be as true for birth parents, particularly birth mothers, whose health can affect a child in ways other than genetic disorders. As important as medical information is, the right to privacy of extended relatives who refuse to disclose their records voluntarily should not be invaded, absent compelling reasons to do so.

c. Applicability of Human Immunodeficiency Virus and Other Specific Nondisclosure Statutes

An aspect of invading parents' medical records that merits special attention is whether a parent's human immunodeficiency virus (HIV) status should be subject to disclosure. The vast majority of states now prohibit by statute the disclosure of information related to HIV testing or diagnosis of specific individuals.<sup>373</sup> The proposed limitations on the circumstances under which a parent's records could be released would preclude any need for an exception to the HIV nondisclosure statutes for information on the father's HIV status. HIV is not genetically transmitted, nor has there been any indication that perinatal transmission can occur from an infected father.<sup>374</sup>

Whether an exception to these statutes should be created for release

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373. David A. Hansell, *HIV Antibody Testing: Public Health Issues*, in AIDS PRACTICE MANUAL, at 3-14 n.63 (Paul Albert et al. eds., 3d ed. 1991), lists 45 jurisdictions with HIV confidentiality protection statutes: Alabama, Arizona, Arkansas, California, Colorado, Connecticut, Delaware, District of Columbia, Florida, Georgia, Hawaii, Idaho, Illinois, Indiana, Iowa, Kansas, Kentucky, Maine, Maryland, Massachusetts, Michigan, Missouri, Montana, Nebraska, Nevada, New Hampshire, New Jersey, New Mexico, New York, North Carolina, North Dakota, Ohio, Oklahoma, Oregon, Rhode Island, South Carolina, South Dakota, Texas, Utah, Vermont, Virginia, Washington, West Virginia, Wisconsin, and Wyoming.

374. Cf. S. Sheppard, *Medical and Public Health Overview of HIV Infection*, in AIDS PRACTICE MANUAL, *supra* note 373, at 2-9 to 2-14 (summarizing known modes of HIV transmission).

Of course, in cases of incest or needle-sharing between an HIV-infected father and a child, transmission could occur. Many states include exceptions in their nondisclosure statutes that would permit disclosure to sexual partners or needle-sharing partners. See Hansell, *supra* note 373, at 3-15 to 3-16. These circumstances would be highly unlikely to involve an infant, however. Performing a blood test on an older child should provide the necessary information. See Sheppard, *supra*, at 2-25 (90% of infected people register antibody-positive on standard tests 12 weeks after exposure; 95% register positive after six months). The extent to which a problem of false negative results can be alleviated with other tests is currently being explored. *Id.* at 2-26. If false negatives remain a significant problem, however, states should consider an exception to the disclosure statutes for all child incest victims, whose rights to critical medical treatment must clearly override their abuser's right to privacy.

of a birth mother's records, however, requires closer examination. Transmission of HIV from an infected mother to a child can occur *in utero*, during the birth process, and through breast feeding.<sup>375</sup> Experts currently suggest that between twenty to fifty percent of babies born to HIV-infected mothers will themselves contract AIDS.<sup>376</sup> The current status of HIV testing of infants would render invasion of the mother's medical records unnecessary in many instances. A child who was relinquished for adoption at birth could be given a blood test shortly after birth that would indicate whether the mother was HIV infected.<sup>377</sup> Because the child may carry the mother's antibodies for up to fifteen to eighteen months after birth, this test will not determine conclusively whether the child is HIV positive,<sup>378</sup> but it would provide the same information on HIV status as the mother's medical records. Recently, a new test has been developed, which detects a protein in the infant's immune system known as IgA.<sup>379</sup> Scientists have reported that this test can reliably detect HIV infection in infants as young as three to six months old.<sup>380</sup> Because the IgA test detects a protein formed only by the infant and not by the mother, it can confirm whether the infant (as opposed to the mother) is infected.<sup>381</sup> Unfortunately, this test is not 100% accurate,<sup>382</sup> but it would provide a reasonably reliable method for determining HIV status for most children over six months of age.

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375. Sheppard, *supra* note 374, at 2-10.

376. See Sheppard, *supra* note 374, (rate of transmission from infected mother to infant is 25% to 50%); *Mandatory Screens of Pregnant Women, Babies Opposed in Report by Institute of Medicine*, AIDS POL'Y & L., Jan. 23, 1991, at 1, 2 [hereinafter *Mandatory Screens of Pregnant Women*] (reporting 25% to 35% risk of transmission); *Michigan Study Says Black Mothers Are More Likely to be HIV Infected*, AIDS POL'Y & L., Feb. 6, 1991, at 7, 7 (25% to 35% of infants will become infected); *NIH Agency Begins Study of AZT for Effectiveness in Pregnancy*, AIDS POL'Y & L., May 29, 1991, at 2, 2 [hereinafter *NIH Agency Begins Study of AZT*] (70% to 90% of infants born to HIV-positive women are not infected with the virus).

377. "All babies born to HIV-positive mothers initially have HIV antibodies." *Infant Diagnosis Difficulty Outlined at Medical Meeting*, AIDS POL'Y & L., Feb. 24, 1988, at 7, 7; Telephone Interview with Jerry Kudlac, Director of Immunology and Metabolic Diseases Screening, Public Health Laboratory, Oklahoma Department of Public Health (July 3, 1991). The standard HIV test given to newborns is an HIV-antibody test that does not "differentiate between truly infected babies and those who are carrying passively acquired maternal antibodies." *Mandatory Screens of Pregnant Women*, *supra* note 376, at 1.

378. Sheppard, *supra* note 374, at 2-26 (up to 18 months); *Mandatory Screens of Pregnant Women*, *supra* note 376, at 1 (mother's antibodies may persist for up to 15 months after birth).

379. Lawrence K. Altman, *Infants' AIDS Test Is Called Reliable*, N.Y. TIMES, June 19, 1991, at A5.

380. *Id.*

381. *Id.*

382. *Id.* Researchers performing IgA tests on infants ranging from one day to six months and older found that of 47 infants confirmed HIV positive at 15 months old by HIV antibody testing, 45 were determined HIV positive by the earlier IgA test. *Id.*

The question then becomes whether an exception to the HIV non-disclosure statutes is warranted for access to a birth mother's records in circumstances in which adequate information cannot be obtained from these tests. It is. Although HIV antibodies from the mother can be carried by the child for up to fifteen to eighteen months, an infant could also stop carrying those antibodies as early as two to three months old, and thus the HIV antibody test is most reliable if performed at or shortly after birth.<sup>383</sup> Thus a hiatus of several months exists between the time when the HIV antibody test may not be reliable and the period when the IgA test is not yet reliable. Moreover, access to information on the mother's positive HIV status, when she was unavailable or unwilling to volunteer it, might give some indication of risk in instances in which a test on the child showed a false negative.<sup>384</sup> Disclosure of her HIV status would only be possible, of course, if the birth mother had not chosen an anonymous testing site, and in such cases it could be argued that disclosure to one adoption agency or intermediary would not greatly widen the circle of those with access to the information, at least in a "closed adoption" in which her identity was unknown to adoptive parents. A partial analogy for such an exception may be found in many states' exceptions allowing physicians or public health officials to notify spouses or partners so that HIV testing and early treatment may be attempted.<sup>385</sup>

In examining the benefits of such a disclosure exception, it must be acknowledged that there is some debate about whether infants should be treated until their own HIV status is confirmed. Many pediatricians believe that because current therapies for HIV expose infants to significant toxicity and substantially fewer than half of infants born to HIV-infected mothers are likely to be infected, the medical benefits do not outweigh the risk of treatment.<sup>386</sup> Other experts point to recent studies which suggest that combining azidothymidine (AZT) with other drugs can minimize the drug's toxicity, and conclude that "early intervention with

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383. Telephone Interview with Jerry Kudlac, *supra* note 377.

384. See Altman, *supra* note 379, at A5, regarding initial reliability studies on the IgA tests. Available information indicates that the commonly used HIV antibody tests for both adults and children can yield false negatives, during a period shortly after infection, Sheppard, *supra* note 374, at 2-25 (reporting that 90% of infected persons register positive 12 weeks after infection and that 95% register positive six months after infection), and also during dormant states when the antibodies may temporarily disappear, see ADOPTION FACTBOOK, *supra* note 86, at 130. In one instance a child of an HIV-infected mother did not test positive until the child was five years old. Telephone Interview with Professor Leonard Sandler, University of Iowa College of Law (June 20, 1991).

385. Hansell, *supra* note 373, at 3-15 to 3-16.

386. See *Mandatory Screens of Pregnant Women*, *supra* note 376, at 2 (possibility and effects of long-term toxicity uncertain); *NIH Agency Begins Study of AZT*, *supra* note 376, at 2 (AZT may create risk of cancer in fetus).

certain drugs can be beneficial in the treatment of infants with AIDS."<sup>387</sup> Knowledge of the possibility of HIV infection, however, would at least alert adoptive parents to the need to repeat testing and to watch for early symptoms, so that treatment can begin as early as possible.

Although proper medical care for the infant would be the paramount justification of a limited birth-mother exception to nondisclosure statutes, in cases where adequate information could not otherwise be obtained, another consideration is making an appropriate placement for the child. One scholar clearly opposed to broad disclosure exceptions concedes that the burden, both emotional and financial, of caring for an HIV-infected child may justify full disclosure of the child's HIV status to prospective adoptive or foster parents.<sup>388</sup> At least two states have specific exceptions to their HIV nondisclosure statutes that allow disclosure of information to adoptive parents, exceptions that could be read broadly to apply to disclosure of a biological mother's HIV status.<sup>389</sup>

Given the limited circumstances under which disclosure of the mother's records would be necessary, the negative effects of creating an exception to the nondisclosure statutes must be carefully weighed. Because AIDS creates an extraordinary risk of discrimination,<sup>390</sup> the concern that knowledge of the exception might prompt a birth mother to forgo HIV testing, or alternatively, choose an option other than legal adoption, is of special significance. In many states, of course, HIV testing is available anonymously; in others, anonymous testing is accomplished through the use of pseudonyms.<sup>391</sup> A mother considering relinquishing her child might choose this option rather than avoid testing. Nonetheless, if the exception significantly affects the willingness of pregnant women to be tested, the adverse consequences to their own

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387. *Newborn Testing, Treatment Under Study in New York State*, AIDS POL'Y & L., Oct. 17, 1990, at 4, 5 [hereinafter *Newborn Testing*] (reporting that National Cancer Institute's Pediatric Branch could not definitively conclude, based on current studies, that an antiretroviral agent should be given to newborns with AIDS, but there is support for such a strategy).

388. Hansell, *supra* note 373, at 3-17.

389. See MO. ANN. STAT. § 191.656(1)(1)(c) (Vernon Supp. 1991); N.Y. PUB. HEALTH LAW § 2782(1)(h) (McKinney Supp. 1991).

390. See *supra* note 67 and accompanying text. See generally Mark Barnes, *Discrimination in Places of Public Accommodation: Access to Health Care, Education, and Other Services*, in AIDS PRACTICE MANUAL, *supra* note 373, at 11-1 (reporting denial of admission to schools, refusal of medical and dental care); Geoffrey S. Cline, *Discrimination Against Persons with AIDS in Employment: Issues for Practitioners and Clients*, in AIDS PRACTICE MANUAL, *supra* note 373, at 10-1 (isolation from coworkers); John Hammell, *Housing Discrimination*, in AIDS PRACTICE MANUAL, *supra* note 373, at 12-1 (refusal to repair, refusal to rent, refusal to assist in resale).

391. Hansell, *supra* note 373, at 3-4. For example, in Colorado it is reported that "Nancy Reagan" has received hundreds of HIV antibody tests. *Id.* at 3-4 n.9.

health as well as their babies' health<sup>392</sup> would not justify it. In truth, the disclosure exception itself probably would not greatly affect a mother's choice regarding adoption, because a mother who is knowledgeable about the exception would also in all probability be aware that subsequent testing of the child might reveal her own infection.<sup>393</sup>

On balance, the current deficiencies of infant testing make it worth the risk to adopt a very limited disclosure exception for a mother's HIV status to adoption agencies or intermediaries, only upon court order and only when equivalent information cannot be accurately obtained by testing the child. Nevertheless, the decision will be a difficult one for each state. Indeed, the rapid advances in the field of infant testing may soon alter the balance and render such an exception unnecessary.

A similar analysis must underlie consideration of exceptions to other specific nondisclosure statutes. For example, most states require that the results of testing for venereal disease be kept confidential.<sup>394</sup> Some maternal venereal diseases, such as syphilis, can have devastating health consequences for a child.<sup>395</sup> Although newborns can undergo screening and confirmation tests that can detect a mother's antibodies in an infant for up to six to ten months,<sup>396</sup> these tests may report false negative results.<sup>397</sup> Because the treatment for infants, penicillin, is nontoxic and can be given safely when there is an indication that the child is at risk for syphilis, it is important to know whether there is any risk, so that infants may be treated promptly. Experts recommend that infants who cannot be evaluated fully be treated anyway.<sup>398</sup> A more detailed analysis of the current sophistication of syphilis and other venereal-disease testing and treatment is necessary to determine whether testing would fully obvi-

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392. Although most experts at this time oppose mandatory screening of pregnant women, they stress the importance of encouraging and making available voluntary testing to enhance the early treatment for both the mother and the child. See *Mandatory Screens of Pregnant Women*, *supra* note 376, at 1-2. Moreover, knowledge of infection assists mothers in making appropriate choices about breast feeding and other health care issues for their newborns.

393. For a discussion of the justification for such testing, see *infra* notes 399-409 and accompanying text.

394. See, e.g., WASH. REV. CODE ANN. § 70.24.105 (West Supp. 1991); see Gostin, *supra* note 67, at R:47 to R:48.

395. Francis Livingston, *Sexually Transmitted Diseases in Pregnancy*, STD BULL., Apr. 1990, at 3, 3-10 (noting that congenital syphilis can cause mental retardation, blindness, deformities, blood disorders, and death).

396. Telephone Interview with Kay Holt, Manager, Clinical Services, STD-HIV Division, Oklahoma Public Health Department (July 3, 1991).

397. David H. Dorfman & Joy H. Glaser, *Congenital Syphilis Presenting in Infants After the Newborn Period*, 323 NEW ENG. J. MED. 1299, 1301 (1990).

398. Centers for Disease Control, *Sexually Transmitted Disease Treatment Guidelines*, 38 MORBIDITY & MORTALITY WKLY. REP. 10-11 (Supp. 8 1989).

ate an exception to the nondisclosure statutes for syphilis or other venereal diseases.

d. Conducting Diagnostic Tests Upon the Adoptee

"Reasonable efforts" to investigate may, and in many instances should, include the obligation to direct that certain diagnostic tests be administered to the adoptee. For example, an agency handling the adoption of a newborn should take steps to ensure that the standard newborn diagnostic testing has been performed.<sup>399</sup> Failure to ensure that these tests are performed can lead to inappropriate medical care by adoptive parents and pediatricians and has caused tragic results.<sup>400</sup> Moreover, it may be important in some instances to obtain these results early in the process in order to avoid inappropriate placement.<sup>401</sup> When older children are placed for adoption, the agency should ensure that a recent physical and psychological examination has been conducted.<sup>402</sup> Whenever available information suggests that a child may be at risk for something not detectable by standard screening, the agency or adoption intermediary should be responsible for ensuring that necessary testing takes place.<sup>403</sup>

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399. Because agencies handling infant adoptions often have legal custody of an infant from shortly after birth, and have sole access to the medical records, it is critical that they be responsible for ensuring that all standard newborn testing is performed and for communicating the results to adoptive parents. Adoptive parents and pediatricians often assume testing has been performed and that they would be notified if results were adverse. Without access to the child's name at birth, they have no means to double-check. It is similarly critical in independent adoptions for the attorney representing the prospective adoptive parents to undertake this task.

400. See *Foster v. Bass*, 575 So. 2d 967, 969-71 (Miss. 1990) (relating that adopted child suffered permanent brain damage from phenylketonuria (PKU) because adoptive parents and child's pediatrician assumed test for PKU had been performed).

401. For example, if a child tests HIV positive, it is important to know this information early. Only through such early disclosure can the adoption intermediary provide appropriate counseling and ensure that the prospective adoptive family understands the risks and is capable of meeting the needs of the child. Although this knowledge may make placement more difficult, there are families willing to adopt babies who are HIV positive. See *San Francisco*, *supra* note 140, at 7 (noting that program in Yonkers, N.Y. placing HIV-positive children abandoned by parents reports 52% of foster families were willing to adopt HIV children placed with them).

402. Older children often become available for adoption through parental rights termination proceedings. This suggests that such children may be at particularly high risk for medical or psychological problems that must be assessed.

403. Both agencies and private attorney adoption intermediaries are capable of building the cost of such testing into their fee structures. It is important that they, and not just the adoptive parents, have the responsibility for ensuring that necessary testing is conducted. Making an appropriate placement is the responsibility of the agency or intermediary, and adoptive parents may not be sufficiently informed of the child's previous care or relevant history to assess the testing that is needed. If the need for further testing comes to light after the child has already

Because medical testing of a child in many cases reveals information concerning the medical history of other family members, most frequently the mother, privacy concerns must again be considered. Testing for HIV status and syphilis, for example, will reveal the mother's infection.<sup>404</sup> It may seem ludicrous to examine thoroughly the circumstances under which a mother's medical records can be obtained,<sup>405</sup> and yet advocate routine testing of her child that will disclose the same information. Nevertheless, the child is an independent person with his own right to appropriate medical care, and the fact that information about another is a byproduct of testing the child should not restrict the child's access to proper medical treatment. To forgo syphilis testing, for example, would subject a child to the risk of severe retardation, blindness, or death, all of which can often be prevented by timely treatment, and thus could never be justified out of respect for a mother's privacy rights.<sup>406</sup> Medical ethicists are now debating whether mandatory HIV testing of newborns would be an unwarranted invasion of the mother's right to privacy.<sup>407</sup> Even if this is determined to be the case, adoption creates special circumstances which dictate that such testing be conducted. A child placed for adoption will no longer be cared for by the birth mother, whose knowledge of her own lifestyle might prompt her to seek appropriate medical care for the child earlier than an adoptive parent, who does not know that HIV infection might exist. The need for the information to facilitate appropriate placement is, of course, absent for children who will remain in a parent's care. Moreover, fairness to prospective adoptive parents, who should be advised of the potential emotional and financial burden

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been placed, but before the adoption is finalized, the adoption intermediary's obligation could be satisfied by ensuring that the prospective adoptive parents are appropriately counseled and obtain the proper tests.

404. See *supra* notes 377-82 (HIV), 396 (syphilis) and accompanying text.

405. See *supra* notes 364-69, 375-98 and accompanying text.

406. Livingston, *supra* note 395, at 3, 6, 9. Almost all states now require that pregnant women be tested for syphilis, so that the mother can be treated with penicillin as early during the pregnancy as possible. *Id.* Because these tests may report false-negative results or infection may occur thereafter, experts recommend that all infants be tested at birth, and that additional tests be performed on all febrile infants, including those who tested negative at birth. Dorfman & Glaser, *supra* note 397, at 1299, 1301.

407. The Institute of Medicine's Committee on Prenatal and Newborn Screening for HIV Infection opposes mandatory HIV antibody screening of newborns because the current newborn tests reveal the mother's infection status, finding it "ethically unacceptable" to conduct such a test without the mother's consent. *Mandatory Screens of Pregnant Women*, *supra* note 376, at 1-2. The Committee concluded, however, that its recommendation should be "re-evaluated if either a definitive neonatal test or 'safe, effective treatment that cured infection' is developed." *Id.* at 2.

At least one state, Rhode Island, does require testing of newborns of high-risk mothers even without the mother's consent. R.I. GEN. LAWS § 23-6-14(a) (1989 & Supp. 1991); see Hansell, *supra* note 373, at 3-10.



and receive appropriate counseling,<sup>408</sup> dictates that HIV testing be performed.<sup>409</sup>

e. Mandatory Testing of Biological Parents or Relatives

Some might propose that if dissemination of health information is so vital in the adoption context, biological relatives, and particularly mothers, should be compelled in certain circumstances to undergo diagnostic testing, either prior to childbirth or even after delivery and relinquishment.<sup>410</sup> While conveying accurate medical information to adoptive parents and adoptees is vital, this is where the line should be drawn. Any effort to *force* biological parents to undergo medical testing would constitute an outrageous invasion of their right to privacy and personal autonomy.

American courts have often recognized, both under the common law and the federal Constitution, that the right to privacy includes a right of bodily integrity, and a right to accept or forego medical treatment.<sup>411</sup> The United States Supreme Court has afforded the highest level of constitutional protection to the privacy interest in autonomous per-

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408. See ADOPTION FACTBOOK, *supra* note 86, at 131; Hansell, *supra* note 373, at 3-17.

409. Some adoption agencies currently test all newborns; others test only those who are considered high risks. ADOPTION FACTBOOK, *supra* note 86, at 131. Comprehensive testing would appear to be the safer course, as accurate information on high risk factors (multiple sex partners, intravenous drug use) may be difficult to obtain. The cost may not be much of a factor in many states, as several already test all infants anonymously for the HIV virus at birth. Scott H. Isaacman, *Neonatal HIV Testing: Governmental Inspection of the Baby Factory*, 24 J. MARSHALL L. REV. 571, 572-574 (1991) (almost all states and territories now participating in joint neonatal HIV serosurveillance program with the United States Department of Health and Human Services Centers for Disease Control); *Newborn Testing*, *supra* note 387, at 5; Telephone Interview with Jerry Kudlac, *supra* note 377.

410. Lest this section appear to be tilting at windmills, during a meeting of commissioners in the summer of 1990 it was suggested that a proposed revision of the Uniform Adoption Act require blood testing and DNA profiles of biological parents, and that parents refusing such tests should be "punished" in some way. Telephone Interview with Joan Hollinger, *supra* note 16. Some adoption agencies now require all birth mothers to undergo HIV testing, while others now require high risk mothers to submit to the test. ADOPTION FACTBOOK, *supra* note 86, at 131; see also OHIO REV. CODE ANN. § 3107.12 (Anderson 1989) (permitting investigator to request parental medical examination).

411. *In re A.C.*, 573 A.2d 1235, 1243-47 (D.C. 1990); e.g., *United States v. Charters*, 829 F.2d 479, 491 & nn. 18-19 (1987), *aff'd on reh'g*, 863 F.2d 302 (4th Cir. 1988), *cert. denied*, 110 S. Ct. 1317 (1990); *Bee v. Greaves*, 744 F.2d 1387, 1392-93 (10th Cir. 1984), *cert. denied*, 469 U.S. 1214 (1985); *Canterbury v. Spence*, 464 F.2d 772, 780 (D.C. Cir.), *cert. denied*, 409 U.S. 1064 (1972); *In re Bryant*, 542 A.2d 1216, 1218 (D.C. 1988); *Crain v. Allison*, 443 A.2d 558, 561-62 (D.C. 1982); *Mohr v. Williams*, 95 Minn. 261, 268, 104 N.W. 12, 14 (1905); *Schloendorff v. Society of N.Y. Hosp.*, 211 N.Y. 125, 129-30, 105 N.E. 92, 93 (1914); see Lawrence J. Nelson, *Reproductive Choices*, 1 BIO LAW, at R:87 to R:89 (James F. Childress et al. eds., Supp. July 1989). For additional authorities discussing the right of bodily integrity and the right of autonomy as elements of the right to privacy, see *supra* notes 40-41.

sonal decisionmaking,<sup>412</sup> from which the right of bodily integrity is derived.<sup>413</sup> Statutes impairing this interest have undergone greater scrutiny by the Court than those that allow collection and disclosure of personal information.<sup>414</sup> Concededly, all of the arguments justifying invasion of a birth parent's medical records, accessing HIV data, and testing the infant could also be made to justify the requirement that birth parents be forced to undergo testing. Yet the greater protection that the Court has given to the autonomy interests included in the right to privacy implicitly recognizes that a forced invasion of one's body would constitute a far greater invasion of the birth parent's personhood.

That a child is or may be adopted does not warrant evisceration of the parent's right to bodily integrity under circumstances in which such testing could not be performed if the child were not to be adopted. "Reasonable efforts" to investigate<sup>415</sup> should in most instances provide adoptive and prospective adoptive parents with the information available to the birth parent. Legally<sup>416</sup> and ethically,<sup>417</sup> forced diagnostic testing of

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412. See, e.g., *Eisenstadt v. Baird*, 405 U.S. 438, 453 (1972); *Griswold v. Connecticut*, 381 U.S. 479, 484-85 (1965).

413. See *supra* notes 40-41 and accompanying text.

414. Compare *Zablocki v. Redhail*, 434 U.S. 374, 383-84 (1978) (employing strict scrutiny analysis) and *Eisenstadt*, 405 U.S. at 453 (same) with *Nixon v. Administrator of Gen. Servs.*, 433 U.S. 425, 458, 462-65 (1977) (state-mandated collection, retention, and disclosure of personal information subjected to less rigorous review) and *Whalen v. Roe*, 429 U.S. 589, 602, 605-06 (1977) (same). In *Whalen* and *Nixon*, statutes were upheld if they served reasonable public interests and contained procedures protecting against unwarranted disclosure. See *supra* notes 44-48, 70-72 and accompanying text.

415. See *supra* notes 342-409 and accompanying text.

416. Recently, the District of Columbia Court of Appeals held that in determining the course of treatment for a dying pregnant woman, "in virtually all cases the question of what is to be done is to be decided by the patient—the pregnant woman—on behalf of herself and the fetus." *In re A.C.*, 573 A.2d 1235, 1237 (D.C. 1990). The court rejected an approach that would balance the interests of the mother against those of the fetus and the state, declaring instead that if the mother is competent and makes an informed decision, "her wishes will control in virtually all cases." *Id.* at 1252. In support of this position, the court observed that courts have consistently honored the principle that a significant intrusion upon one person's bodily integrity cannot be compelled for the benefit of another person's health, nor even to save another's life. *Id.* at 1243-44 (citing *Bonner v. Moran*, 126 F.2d 121, 122 (D.C. Cir. 1941) and *McFall v. Shimp*, 10 Pa. D. & C.3d 90 (Allegheny County Ct. 1978)); see also *Taft v. Taft*, 388 Mass. 331, 334-35, 446 N.E.2d 395, 397 (1983) (vacating order that required pregnant women to submit to "purse string" surgery, concluding that no compelling circumstances justified overriding her religious objections and her constitutional right of privacy). Although it is true that the invasions in these cases involved surgery, which may be more significant than coerced diagnostic tests, the consequence of noncoercion involved a high risk of death to another. In the adoption context, the availability of other avenues for information gathering and investigation militates against intrusion. But cf. *In re President & Directors of Georgetown College, Inc.*, 331 F.2d 1000, 1008 (D.C. Cir.) (ordering mother to undergo transfusion, in part because of her duty to her living children), *cert. denied*, 377 U.S. 978 (1964); *Jefferson v. Griffin Spalding County Hosp. Auth.*, 247 Ga. 86, 90, 274 S.E.2d 457, 460 (1981) (*per curiam*) (ordering

the birth parents should not be required.<sup>418</sup> Agencies and other adoption intermediaries should instead be encouraged, and in fact obligated, to provide appropriate counseling to birth parents to encourage voluntary testing where such testing would prove beneficial for the health of either the mother<sup>419</sup> or the child, but must respect a birth parent's refusal to consent to testing.

#### f. Inefficacy of Statutory Parental Duty to Disclose

Several state statutes include a general directive that a person who surrenders or places a child for adoption should complete a medical history form.<sup>420</sup> None of these statutes, however, appear to create a statu-

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cesarean delivery over mother's religious objections where medical testimony indicated cesarean would improve both mother's and infant's chance of survival); *Raleigh Fitkin-Paul Morgan Memorial Hosp. v. Anderson*, 42 N.J. 421, 423, 201 A.2d 537, 538 (per curiam) (ordering blood transfusion over religious objection of mother, to save life of both mother and fetus), *cert. denied*, 377 U.S. 985 (1964); *In re Jamaica Hosp.*, 128 Misc. 2d 1006, 1007-08, 491 N.Y.S.2d 898, 899-900 (Sup. Ct. 1985) (ordering blood transfusion over mother's religious objections, finding state's interest in fetus outweighed patient's); *Crouse Irving Memorial Hosp., Inc. v. Paddock*, 127 Misc. 2d 101, 102-03, 485 N.Y.S.2d 443, 444-45 (Sup. Ct. 1985) (ordering transfusion over mother's religious objections to save both mother and child).

417. The Committee on Prenatal and Newborn Screening for HIV Infection, organized by the federal government's Institute of Medicine, has concluded that ordering mandatory testing of pregnant women in general for HIV infection would be "ethically unacceptable." *Mandatory Screens of Pregnant Women*, *supra* note 376, at 1; see *Hansell*, *supra* note 373, at 3-9 n.34 (opposing mandatory HIV testing for pregnant women and noting that only two states, Delaware and Florida, currently require pregnant women to undergo HIV testing). *But cf.* DEL. CODE ANN. tit. 16, § 708 (Supp. 1990) (requiring HIV testing for pregnant women); FLA. STAT. ANN. § 384.31 (West Supp. 1991) (same).

418. Although there might be general consensus that requiring birth parents to undergo a DNA profile or battery of genetic tests would be wrong, a far more difficult issue is presented by a requirement that a birth mother undergo HIV testing. As discussed previously, there are circumstances in which tests on the infant will reveal false negatives. See *supra* notes 382-84 and accompanying text. Even though I have argued that the risks to these infants justify invading the birth mother's records in cases in which this is suspected, there is a qualitative difference between obtaining results of a test she took voluntarily and forcing her to take the test. Forced testing creates information that did not otherwise exist, information that could cause the birth mother extreme anxiety and stress. Medical ethicists note that the right of autonomy includes the right to choose not to receive information. *Huggins et. al.*, *supra* note 244, at 6 (describing ethical and legal considerations in testing for Huntington's Disease). The current status of testing and treatment of infants for HIV is such that mandatory testing of all pregnant women is not generally approved. See *supra* note 417. While adoption does create a different situation, information about the mother's lifestyle can be transmitted, and adoption intermediaries could follow a policy of recommending to adoptive families repetition of the HIV test in those cases in which a birth mother chooses after appropriate counseling not to submit to the test.

419. For example, voluntary testing for HIV or other sexually transmitted diseases would facilitate medical treatment that the mother might need.

420. FLA. STAT. ANN. § 63.082(3)(a) (West 1985); LA. REV. STAT. ANN. § 9:422.13(B)(2) (West 1991); OKLA. STAT. ANN. tit. 10, § 60.5A (West 1987).

tory duty to disclose requested information that would be punishable if violated.<sup>421</sup> One commentator has suggested that imposing a duty on parents to disclose their own health histories would constitute a significant invasion of privacy.<sup>422</sup> Although it is clearly desirable for birth parents to cooperate in the collection of a complete medical history, an attempt to impose sanctions for incomplete compliance by criminal prosecution or contempt proceedings would likely prove ineffective and could raise significant privacy concerns.

Requiring that only trained professionals collect information,<sup>423</sup> developing protocols that enhance cooperation, and placing the above-described "reasonable efforts" duty on intermediaries are more positive and effective methods of acquiring complete and accurate information than sanctions. If properly approached by a sensitive and well-trained professional, most birth parents should be willing to provide medical history.<sup>424</sup> It seems unlikely that those who refuse would comply due to a remote threat of enforcement, and compelled cooperation could create a significant risk that parents would offer inaccurate information.<sup>425</sup> The difficulty of proving that parents intentionally provided inaccurate or incomplete information would dissuade prosecutors from initiating enforcement proceedings. Moreover, publicity from a few token enforcement prosecutions or contempt proceedings as a way of motivating

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421. See, e.g., OKLA. STAT. ANN. tit. 10, § 60.5A (West 1987) (mandating that person required to consent to adoption complete medical history form when ordered by the court). But see statutes cited *infra* note 491 (creating sanctions for noncompliance with investigation and disclosure statutes); cf. IND. CODE ANN. § 31-3-4-19 (Burns Supp. 1991) (creating a misdemeanor, possibly applicable to birth parents, for knowingly supplying false information to a medical history).

422. Schiffer, *supra* note 33, at 719; see also *ASHG Report*, *supra* note 290, at 1010 ("right to privacy includes the right of any party to refuse to enter into or cease to participate in the process of gathering genetic information").

423. See *supra* notes 334-38 and accompanying text.

424. One report examining independent adoptions indicated that 65% of birth fathers agreed to supply medical/genetic information. Thomas J. Mick, *Social Work Practice Issues, in GENETIC FAMILY HISTORY*, *supra* note 1, at 31, 35. While parents who relinquish a child voluntarily are in all likelihood going to be the most willing to cooperate, cooperation under other circumstances can be enhanced by adopting more intensive efforts than have heretofore been undertaken, and acquiring information early in the process in involuntary proceedings. See *supra* note 356 and accompanying text.

425. A parent who simply does not want to take the time or be bothered (for example, a birth father who has had no significant relationship with the mother and feels no connection to the child) could in all likelihood be persuaded to comply if approached properly and persistently. A parent with a more deep-seated reason for refusal, such as fear of HIV discrimination to the parent or fear that the child will be unadoptable, might be persuaded through appropriate counseling regarding confidentiality of the information or availability of adoptive homes. Nevertheless, a parent whose serious concerns cannot be identified or overcome is unlikely to risk discrimination, criminal prosecution, or other adverse consequences because of a remote chance of sanctions for noncompliance.

compliance might simply deter birth parents from considering legal adoption.<sup>426</sup>

Imposing criminal sanctions against parents or other relatives for failure to disclose their own medical histories also unnecessarily invades privacy. Individuals possess no absolute right to withhold information of a personal nature, absent a threat of self-incrimination.<sup>427</sup> Governmental agencies, for example, frequently require disclosure of health information on applications for employment or other benefits. Nevertheless, the adverse consequence to a job or benefits applicant from failure to provide medical information is denial of the job or benefits, a situation not closely analogous to adoption because adoption benefits the child and denial would not be appropriate.<sup>428</sup> Courts may require testimony from witnesses regarding their own medical and psychological history when relevant to the issues before the court. In judicial proceedings, however, particularly in discovery<sup>429</sup> and to some extent under the rules of evidence,<sup>430</sup> the court considers the adverse consequences of ordering dis-

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426. An indication of the deterrence factor can be seen in the concern of professionals in drug treatment programs that publicity surrounding prosecutions of maternal substance abusers will discourage women from seeking prenatal care or drug treatment. Roberts, *supra* note 273, at 1449-50 & n.157; Kennedy, *supra* note 273, at 577; Rubenstein, *supra* note 273, at 151-52.

427. The Fifth and Fourteenth Amendments of the United States Constitution, of course, prevent both the federal and state governments from compelling a person to respond to governmental inquiry when disclosure could give rise to criminal liability. See EDWARD W. CLEARY ET AL., MCCORMICK ON EVIDENCE §§ 119, 121(a) (3d ed. 1984).

428. For an example of statutes limiting the effect of nondisclosure on finalization of the adoption, see OHIO REV. CODE ANN. § 3107.12(D)(5) (Anderson 1989) (providing that neither failure of an investigator to obtain history "nor the refusal of a biological parent to supply information shall invalidate, delay, or otherwise affect the adoption").

429. Federal Rule of Civil Procedure 26(c) authorizes a court to prohibit discovery of certain matters through issuance of a protective order if justice so requires, in order to protect either a party or a nonparty from annoyance, embarrassment, or oppression. FED. R. CIV. P. 26(c). The Supreme Court has specifically approved the use of protective orders to protect the privacy interests of both litigants and nonlitigants. See *Seattle Times Co. v. Rhinehart*, 467 U.S. 20, 30-36 (1984); see also *Williams v. Thomas Jefferson Univ.*, 343 F. Supp. 1131, 1132 (E.D. Pa. 1972) (refusing to require defendant hospital to supply names of women who had received abortions in 1969 on grounds that women's privacy interests outweighed possible impeachment benefit to plaintiff); cf. *Farnsworth v. Proctor & Gamble Co.*, 758 F.2d 1545, 1547 (11th Cir. 1985) (granting protective order to nonparty, Centers for Disease Control (CDC), denying plaintiff in product liability case access to names of women who participated in CDC toxic shock syndrome study and who had not consented to disclosure); *Coleman v. American Red Cross*, 130 F.R.D. 360, 362 (E.D. Mich. 1990) (denying motion to compel and granting protective order to prohibit disclosure of name of HIV-infected donor in suit against blood supplier).

430. FED. R. EVID. 611(a); see GLEN WEISSENBERGER, WEISSENBERGER'S FEDERAL EVIDENCE § 611.1, at 250 (1987) (commenting that rule 611 is "designed to encourage flexibility in the reception of evidence by promoting the efficient determination of the court without unnecessary abuse of the dignity of the witness").

closure—potential embarrassment, risk of harassment, invasion of privacy—and weighs these against the necessity that information be disclosed by the witness to determine whether disclosure should be compelled. Given the alternatives for obtaining information in an adoption investigation and the potential ineffectiveness of sanctioning nondisclosure, privacy concerns outweigh any slight benefits to be gained.<sup>431</sup>

g. Confidentiality and Immunity for Information Disclosed

To ensure accurate collection of complete medical and social history, state statutes must include provisions that ensure the confidentiality of the information. Specifically, legislatures should prohibit the disclosure of medical and social history to anyone other than those specifically authorized to receive it.<sup>432</sup> It must be clear that other access to these records must be limited to the adoption agency or intermediary responsible for collection and retention, court personnel involved in the adoption action, and, if a central registry is established, those personnel necessary to operate the registry. Specifically, law enforcement personnel or prosecutorial staff should *not* have access to these records or to the information contained therein.

Furthermore, these statutes must provide clearly that none of the medical or social history supplied as part of the adoption investigation can be used in any criminal prosecution or civil suit against the birth parents or another biological relative. Prosecution of mothers for substance abuse during pregnancy is a relatively recent phenomenon that could have an alarming effect on the willingness of birth mothers, their relatives, or medical personnel to reveal information that might aid prosecution. Recent studies indicate that since 1987 more than fifty criminal cases on such charges as child neglect, delivery of drugs to a minor, or criminally negligent homicide have been brought against women for substance abuse during pregnancy.<sup>433</sup> The specter of prosecution would negatively affect any mother's willingness to reveal substance abuse or any

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431. It may seem odd to advocate a limited ability to compel medical personnel to release a parent's medical records and yet disfavor sanctions for a parent who refuses to supply that information directly. Nevertheless, sanctions against an uncooperative parent would be less effective than a court order to medical personnel when disclosure is authorized by statute. Medical personnel would be far more likely to reply accurately. Moreover, by analogy to the Fifth Amendment, requiring a person to disclose her own medical and social history seems more intrusive from a privacy standpoint than requiring, in a limited context, a third party to release that sensitive information.

432. See *supra* notes 226-62 and accompanying text.

433. Roberts, *supra* note 273, at 1421 n.5; Rubenstein, *supra* note 273, at 130, 157-60 (citing American Civil Liberties Union Reproductive Freedom Project, State by State Case Summary of Criminal Prosecutions Against Pregnant Women and Appendix of Public Health and Public Interest Groups Opposed to These Prosecutions (Oct. 29, 1990) (memorandum)).

other activity that might create fetal risk during pregnancy.<sup>434</sup> Information suggesting physical or sexual abuse by a parent or other relative could also prompt criminal charges. An additional concern is the emerging recognition of civil liability in favor of a child against a biological mother for prenatal injury due to allegedly negligent conduct.<sup>435</sup> The possibility that a parent might not provide this type of information is of particular concern because information regarding prenatal substance abuse or child abuse is crucial to the child's proper diagnosis and medical treatment.<sup>436</sup> Use immunity, which would preclude subsequent use of the "testimony," *i.e.*, the statements or recorded information given to an adoption intermediary for purposes of collecting medical and social history, and derivative evidence, *i.e.*, evidence obtained by using the immunized statements or records,<sup>437</sup> *i.e.*, might foster more accurate and cooperative responses.

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These cases are often referred to collectively as "fetal abuse" cases, although the specific charges brought will vary. Roberts, *supra* note 273, at 1421 n.5.

434. Following several publicized prosecutions of substance abusers for "fetal abuse," professionals in drug treatment programs reported that many clients suggested they would not divulge substance abuse to their obstetricians for fear of prosecution, or would decline prenatal care. Rubenstein, *supra* note 273, at 151-52.

435. In *Grodin v. Grodin*, 102 Mich. App. 396, 301 N.W.2d 869 (1980), the Michigan Court of Appeals found that a mother could be held liable to her child for a negligently inflicted prenatal injury. *Id.* at 401, 301 N.W.2d at 871. The mother in *Grodin* was alleged to have taken the medication tetracycline during pregnancy, causing damage to the child's teeth. *Id.* at 398, 301 N.W.2d at 869. The case was remanded for a determination whether the mother's actions were negligent. *Id.* at 401, 301 N.W.2d at 871. Several commentators have applauded recognition of a right of a child against the mother for prenatal injuries. See, e.g., John A. Robertson, *Procreative Liberty and the Control of Conception, Pregnancy, and Childbirth*, 69 VA. L. REV. 405, 448-49 (1983); Sam S. Balisy, Note, *Maternal Substance Abuse: The Need to Provide Legal Protection for the Fetus*, 60 S. CAL. L. REV. 1209, 1237 (1987); Kennedy, *supra* note 273, at 555; Barbara Shelley, Note, *Maternal Substance Abuse: The Next Step in the Protection of Fetal Rights?*, 92 DICK. L. REV. 691, 710-11 (1988).

More recently, the Illinois Supreme Court flatly rejected recognition of a cause of action by a child against his mother for unintentional infliction of prenatal injuries. See *Stallman v. Youngquist*, 125 Ill. 2d 267, 280, 531 N.E.2d 355, 361 (1988). The court found that recognition of liability would create a legal duty to "effectuate the best prenatal environment possible . . . subject[] to State scrutiny all decisions a woman must make in attempting to carry a pregnancy to term, and infringe[] on her right to privacy and bodily autonomy." *Id.* at 276-78, 531 N.E.2d at 359-60. A number of commentators have taken a similar position against recognition of maternal liability. See Ron Beal, "Can I Sue Mommy?" *An Analysis of a Woman's Tort Liability for Prenatal Injuries to Her Child Born Alive*, 21 SAN DIEGO L. REV. 325, 362-70 (1984); Judith Kahn, Note, *Of Woman's First Disobedience: Forsaking a Duty of Care to Her Fetus—Is This a Mother's Crime?*, 53 BROOK. L. REV. 807, 809 (1987). See generally Thomas N. Flemming, Annotation, *Right of Child to Action Against Mother for Infliction of Prenatal Injuries*, 78 A.L.R.4TH 1082 (1990) (analyzing cases recognizing and refusing to recognize cause of action by child against mother for prenatal injuries).

436. See *supra* notes 114-18, 270-73 and accompanying text.

437. CLEARY et al., *supra* note 427, § 143, at 355.

Transactional immunity, defined as "immunity from prosecution for those transactions about which the witness testified under immunity,"<sup>438</sup> is tempting to consider. Transactional immunity would avoid the problem of explaining fine legal distinctions to birth parents, who by and large would have no legal training, and the comprehensiveness of the immunity would provide more reassurance. It is particularly appealing for maternal fetal-abuse prosecutions, which have been widely criticized by scholars as racist, elitist, sexist, violative of a constitutional right to privacy and equal protection, and totally ineffective.<sup>439</sup> Nevertheless, providing transactional immunity could create a significant risk that mothers who perceive themselves at risk for prosecution, particularly those who are substance abusers, might be coerced, intentionally or unintentionally, to place their babies for adoption. Because transactional immunity would have the effect of subjecting a mother to risk of prosecution only if she chooses to keep her child rather than place the child for adoption, it would unconstitutionally burden her fundamental right to the companionship, care, custody, and "management" of her child.<sup>440</sup> It is likely that this risk of coercion would disproportionately affect poor and minority mothers.<sup>441</sup> This risk outweighs any benefits that transactional immunity might engender. A further undesirable by-product of a broad transactional immunity is that it could hinder prosecution of child abusers.<sup>442</sup>

The inclusion of a use immunity provision will require special care regarding the timing of collection of medical and social history for adop-

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438. *Id.*

439. See, e.g., Kary L. Moss, *Legal Issues: Drug Testing of Postpartum Infants and Newborns as the Basis for Civil and Criminal Proceedings*, 23 CLEARINGHOUSE REV. 1406, 140-13 (1990); Roberts, *supra* note 273, at 1432-37, 1442-56, 1462-76; Molly McNulty, Note, *Pregnancy Police: The Health Policy and Legal Implications of Punishing Pregnant Women for Harm to their Fetuses*, 16 N.Y.U. REV. L. & SOC. CHANGE 277, 303-17 (1987-88); Rubenstein, *supra* note 273, at 146-51. But see, e.g., Robertson, *supra* note 435, at 438-39 (arguing that fetal interests outweigh maternal freedom during pregnancy).

440. The right to participate in the rearing of one's child was recognized as fundamental by the Supreme Court in *Santosky v. Kramer*, 455 U.S. 745, 753, 758-59 (1982). This argument, of course, is analogous to Dorothy Roberts's persuasive argument regarding fetal abuse prosecutions in general, that the risk of prosecution for "fetal abuse" if a child is born alive unconstitutionally burdens the fundamental right to bear a child. See Roberts, *supra* note 273, at 1462-71. Such prosecutions, she observes, do not criminalize the same conduct during pregnancy if the mother chooses to abort. See *id.*

441. Several scholars have noted that prosecutions for "fetal abuse" fall disproportionately on poor women of color. See Moss, *supra* note 439, at 1407, 1412; Roberts, *supra* note 273, at 1421 & nn.5 & 6, 1432-36; Rubenstein, *supra* note 273, at 141-42.

442. If reporting physical or sexual abuse by a partner as part of the adoption process could create transactional immunity for that partner, a potential exists for women to be coerced by their partners to place an abused child for adoption, if the partner fears that prosecution is imminent.



tions that follow involuntary termination of parental rights. Ideally, the process of collecting medical and social history to be used in the event of a subsequent adoption should have no effect on the decision regarding termination. It would be unfair and inappropriate for that information to be used against the parents, but it would also be undesirable for the collection of medical information to block termination and subsequent adoption when this is the appropriate outcome otherwise. Collection of information prior to termination facilitates cooperation,<sup>443</sup> but care should be taken that collection occurs after the prosecutor has already gathered the evidence to be used in the juvenile proceeding, so that immunity does not hamper the state's efforts. Furthermore, care must be taken not to confuse or mislead parents by the collection of medical history. If they are represented in juvenile proceedings, notifying and seeking their attorneys' participation in the collection effort might ensure that their interests are not impaired by the process.

### 3. Manner of Collection and Retention

#### a. Initial Collection

To facilitate comprehensive collection and complete disclosure to adoptees and their adoptive and biological families, the method and timing of the collection and retention of social and medical information need more attention. Several states that have addressed the manner of collection merely require that forms be provided to biological parents or to other persons with information.<sup>444</sup> It is far better to require a trained professional affiliated with an adoption agency, attorney, or obstetrician to conduct a personal interview with the biological parents, legal custodians, or relatives and to prepare a written report or to assist the source of the information in completing these forms.<sup>445</sup> Much of the information sought will require some medical expertise and familiarity with terminology beyond that of the average lay person.<sup>446</sup> Social workers, attorneys,

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443. See *supra* note 356 and accompanying text.

444. See, e.g., ALASKA STAT. § 25.23.185 (1991); LA. REV. STAT. ANN. § 9:422.13 (West 1991) (providing that a person who surrenders a child "shall execute therewith a written statement of family history"); OKLA. STAT. ANN. tit. 10, § 60.5A (West 1987).

445. Requiring a personal interview is the strong recommendation of a social work professional who trains social workers involved in adoption in Wisconsin. See Mick, *supra* note 424, at 34. Ohio suggests that information be obtained through interviews with biological parents or other persons, as well as from available records. See OHIO REV. CODE ANN. § 3107.12(D)(3) (Anderson 1989).

446. Words like "hydrocephalus," "cystic fibrosis," "Huntington's Chorea," or "myasthenia gravis," to name just a few that are contained in Wisconsin's medical history form, may be foreign to even an educated birth parent. See Wisconsin Medical/Genetic Form, *supra* note 268.

paralegals, or nurses, on the other hand, could be trained not only to understand the terminology, but also to ask the follow-up questions that commonly are required to obtain complete information.<sup>447</sup>

It is also important that social and medical information be collected early in the adoption process.<sup>448</sup> Although most states that address the issue do require collection efforts at the time of surrender,<sup>449</sup> prior to placement,<sup>450</sup> or prior to filing the adoption petition,<sup>451</sup> many states fail to address the issue in their statutes or require only that the information be collected prior to finalizing the adoption.<sup>452</sup> Information should be collected much earlier in the process so that it can be transmitted to prospective adoptive parents before placement.<sup>453</sup>

#### b. Duty to Update Information

It is extremely important to provide a reliable conduit for information relevant to genetic disorders that surfaces after the initial investigation.<sup>454</sup> To accomplish this most effectively, both the adoption agency or intermediary who initially conducted the investigation and some governmental entity should be required to add to their records information voluntarily provided by the birth family, the adoptive family, the adoptee or

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447. Often, parents or relatives may not provide accurate information because they are not knowledgeable about the significance of particular symptoms. Questioning about factors such as missing fingers, or a history of infant deaths in the family, or certain unusual facial characteristics may elicit clues to genetic disorders. *See generally* Reiser, *supra* note 239, at 63-67 (outlining basic genetic principles). Explaining the importance of collecting adequate information, as well as applicable confidentiality and immunity provisions, may also overcome initial reluctance to disclose. This type of explanation can be performed far more effectively in person than in print. *See* Mick, *supra* note 424, at 34.

448. *See supra* notes 134-39 and accompanying text.

449. *See* LA. REV. STAT. ANN. § 9:422.13 (West 1991) (at time of voluntary surrender); OKLA. STAT. ANN. tit. 10, § 60.5 (West 1987) (when consent is taken).

450. *See* ARIZ. REV. STAT. ANN. § 8-129(A) (1989) (prior to adoption); ARK. CODE ANN. § 9-9-505(a) (Michie 1991) (prior to placement for adoption); CAL. CIV. CODE §§ 222.26, 224.70 (West Supp. 1991) (prior to placement or, if private adoption, as part of home study); TEX. FAM. CODE ANN. § 16.032(a) (West Supp. 1991) (prior to placement); WASH. REV. CODE ANN. § 26.33.350 (West Supp. 1991) (prior to placement).

451. *See, e.g.*, ALASKA STAT. § 25.23.185(a) (1991) (to be filed "at the time a petition for adoption is filed"); COLO. REV. STAT. § 19-5-207(2) (Supp. 1991) (petition to include medical and social history); MISS. CODE ANN. § 93-17-3 (Supp. 1988) (medical information to accompany petition).

452. *See, e.g.*, CONN. GEN. STAT. ANN. § 45a-746 (West Supp. 1991) (not later than date of finalization of adoption); KY. REV. STAT. ANN. § 199.520(4)(a) (Michie/Bobbs Merrill 1991) (same); N.C. GEN. STAT. § 48-25(e) (1991); OR. REV. STAT. § 109.342(1) (1991) (same).

453. *See infra* notes 463-70 and accompanying text.

454. *See* Ball & Omenn, *supra* note 4, at 277-78; Black, *supra* note 85, at 198-99.

the adoptee's descendants,<sup>455</sup> medical personnel, or anyone who provided information in the initial investigation.<sup>456</sup> The agency or adoption intermediary responsible for preparing the initial report should assume this obligation because it is the entity most likely to be contacted by the supplier of supplemental information. It is also wise to require this agency or intermediary to file the supplemental information with the adoption records in the office of the clerk of the court that granted the adoption, and place upon the clerk the same duty to receive and file supplemental information, because the agency or intermediary may not always be known to the person who wishes to supply supplemental information, or to some of the persons entitled to receive it.<sup>457</sup> Unfortunately, only a minority of state statutes currently address this issue.<sup>458</sup>

To provide optimal access to social and medical history, several states have created a central registry,<sup>459</sup> where copies of the medical and social history records are filed for all adoptions taking place in the state, whether through public or private agency or an independent intermediary. A central registry would spare interested parties who may not know the identity of the agency or intermediary or the location of the court from contacting every county court in the state to supplement or request disclosure of medical and social history. At a minimum, if a comprehensive central registry is not created, states should require agencies that cease to function to transfer their records to a designated government department,<sup>460</sup> and should further require any nonagency adoption inter-

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455. See ARIZ. REV. STAT. ANN. § 8-129(B)(2) (1989).

456. See OHIO REV. CODE ANN. § 3107.12 (Anderson 1989).

457. See *id.*

458. See ARIZ. REV. STAT. ANN. § 8-129(B)(2) (1989); CAL. CIV. CODE § 224.73 (West Supp. 1991); CONN. GEN. STAT. ANN. § 45a-746 (West Supp. 1991); FLA. STAT. ANN. § 63-162 (West Supp. 1991); GA. CODE ANN. § 19-8-23 (Michie 1991); ILL. ANN. STAT. ch. 40, para. 1522.4 (Smith-Hurd Supp. 1991); IND. CODE ANN. § 31-3-4-14 (Burns 1987); KAN. STAT. ANN. § 59-2130 (Supp. 1990); MASS. ANN. LAWS ch. 210, § 5A (Law. Co-op. 1981); MICH. COMP. LAWS ANN. § 710.67(2) (West Supp. 1991); MINN. STAT. ANN. §§ 259.47-.49 (West 1987 & Supp. 1992); N.M. STAT. ANN. § 40-7-53 (Michie 1989); N.D. CENT. CODE § 14-15-16 (1991); OHIO REV. CODE ANN. § 3107.12(D)(4) (Anderson 1989); PA. STAT. ANN. tit. 23, § 2905 (Supp. 1991); TEX. FAM. CODE ANN. § 16.032 (West Supp. 1991); W. VA. CODE § 48-4-10 (Supp. 1991); WIS. STAT. ANN. § 48.432 (West Supp. 1991).

459. ALA. CODE § 26-10A-31 (Supp. 1991) (state department of human resources); ALASKA STAT. § 18.50.500(a) (1991) (state registrar attaches information to original birth certificate); IND. CODE ANN. §§ 31-3-1-2, -4-12 to -4-15 (Burns 1987 & Supp. 1991) (state registrar); KAN. STAT. ANN. § 59-2130 (Supp. 1990) (secretary of social and rehabilitation services); NEB. REV. STAT. § 43-107 (Supp. 1990) (Bureau of Vital Statistics); N.C. GEN. STAT. § 48-24 (1991) (Department of Human Resources); UTAH CODE ANN. § 78-30-17 (1987) (Bureau of Vital Statistics); WIS. STAT. ANN. § 48.432 (West Supp. 1991) (Department of Health & Social Services).

460. See, e.g., ARIZ. REV. STAT. ANN. § 8-129(B)(1) (1989); TEX. FAM. CODE ANN. § 16.032 (West Supp. 1991).

mediary to file a copy of all medical and social history reports and supplemental information with this department.<sup>461</sup>

Finally, any entity charged with retaining medical and social history information should be required to keep the records for a period of at least ninety-nine years, to ensure their availability throughout the lifetime of the adoptee and to the adoptee's descendants. Several states have enacted this requirement.<sup>462</sup>

#### 4. Method and Timing of Disclosure

##### a. Disclosure of Information Collected in Pre-adoption Investigation

In order to achieve appropriate adoptive placement and render appropriate medical care, social and medical history must be disclosed to prospective adoptive parents as early as possible in the adoption process. Unfortunately, many states require only that the medical and social history be provided prior to or upon issuance of the final decree of adoption.<sup>463</sup> A final decree may be issued as late as nine months to a year after placement.<sup>464</sup> Were anyone, adoptive parents or the court, to decide that the placement was inappropriate at that point, disruption would cause substantial pain both to the child and to the adoptive family. Moreover, during the time that the child had been in the care of the adoptive family, medical diagnosis and treatment would have taken place without the benefit of the information.

The better approach is therefore to require, as many states have,<sup>465</sup> that medical and social background information be provided to prospective adoptive parents prior to placement. A particularly sensitive approach is to require, as Texas currently does, that this information be

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461. See TEX. FAM. CODE ANN. § 16.032(a), (l), (g) (West Supp. 1991). Such a provision makes great sense because private attorneys who handle independent adoptions retire, change firms, move, and die; thus, it could become difficult within even a few years to track down records if the attorney were the only repository.

462. See, e.g., ARIZ. REV. STAT. ANN. § 8-129(B)(1) (1989); ILL. ANN. STAT. ch. 40, para. 1522.4 (Smith-Hurd Supp. 1991); TEX. FAM. CODE ANN. § 16.032 (West Supp. 1991).

463. See ALA. CODE § 26-10A-19 (Supp. 1991); ALASKA STAT. § 18.50.510 (1986); CONN. GEN. STAT. ANN. § 45a-746 (West Supp. 1991); FLA. STAT. ANN. § 63-162(f) (West Supp. 1991); HAW. REV. STAT. § 578.14.5(c) (Supp. 1990); ILL. ANN. STAT. ch. 40, para. 1522.4 (Smith-Hurd Supp. 1991); KY. REV. STAT. ANN. § 199.520(4)(a) (Michie/Bobbs-Merrill 1991); ME. REV. STAT. ANN. tit. 19, § 533 (West Supp. 1990); N.C. GEN. STAT. § 48-25(e) (1991); OR. REV. STAT. § 109.342(4) (1991); UTAH CODE ANN. § 78-30-17(1) (1987).

464. For example, Oklahoma requires a minimum of six months after the issuance of an interlocutory decree, which often is issued several months after placement, before a final decree of adoption may be issued. See OKLA. STAT. ANN. tit. 10, § 60.15 (West 1987).

465. See, e.g., ARIZ. REV. STAT. ANN. § 8-129(A) (1989); WASH. REV. CODE ANN. § 26.33.380 (West Supp. 1991).

provided "as early as practicable prior to the first meeting of the adoptive parents with the child."<sup>466</sup> It may not be practicable, however, to complete every aspect of "reasonable efforts"<sup>467</sup> prior to placement, particularly in the case of an infant. It may not be feasible or appropriate to contact the birth father or, when necessary, other relatives prior to birth.<sup>468</sup> The results of certain medical tests may not be available, and it may not be appropriate to obtain parental medical records until after relinquishment.<sup>469</sup> Forcing an infant into foster care for a lengthy period to complete all aspects of the investigation may not be in the child's best interests.<sup>470</sup> It seems reasonable, however to require that, at a minimum, an interview with the relinquishing parent, guardian, or other custodian be conducted and that all available information be provided prior to placement, even if completion of the investigation and report does not take place until later. The statutes should require, of course, that in such event the report must be completed as soon as practicable.

Whenever social and medical history is transmitted to adoptive parents, it should be sent in writing and receipt should be acknowledged in writing by the adoptive parents.<sup>471</sup> Providing a copy of the report, with identifying information redacted, of course, allows the parents to refer back and reflect upon the contents. Relying solely on verbal communication is risky, particularly when the communication takes place during the few days between the call that a child is available for adoption and the physical placement of the child<sup>472</sup>—a time of high emotion for all concerned. Moreover, the requirement that a copy of the report signed by the adoptive parents be placed in the court file provides both assurance to

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466. TEX. FAM. CODE ANN. § 16.032(f) (West Supp. 1991).

467. See *supra* notes 342-409 and accompanying text.

468. See *supra* notes 349-56 and accompanying text.

469. See *supra* note 369 and accompanying text.

470. One approach is to exclude nonagency adoptions from the requirement that the information be provided prior to placement. California, for example, requires disclosure prior to placement for agency adoptions and with the home study for a private adoption. CAL. CIV. CODE § 220.26(a) (West Supp. 1991). Adoption intermediaries in independent adoptions, however, also have a duty to facilitate appropriate placement, and prospective adoptive parents in such adoptions have a similar need for access to the information. Adoption intermediaries in private adoptions should therefore have a similar obligation to insure that social and medical history information is provided to prospective adoptive parents prior to placement, to the extent feasible.

471. See TEX. FAM. CODE ANN. § 16.032(h) (West Supp. 1991) (requiring that copy of social and medical history report, signed by the child's adoptive parents, be filed in court records of adoption).

472. It has been the author's experience, based on two of her own adoptions and adoptions by numerous friends and acquaintances, that the call that a child is available for adoption is often the day before, or just a few days before, the infant is to be sent home with the adoptive parents.

the parents that they will receive complete information, and legal protection to the agency or intermediary should an issue arise in the future about whether certain information was communicated.<sup>473</sup>

Several states require that the cost of providing medical and social information be paid by the person requesting it.<sup>474</sup> When such a provision is adopted, a cap or some other mechanism should be included to ensure that the fee is not prohibitive,<sup>475</sup> and an *in forma pauperis* procedure should be available so that no one authorized to receive information is precluded by inability to pay.

When requests for disclosure are made after adoption by adult adoptees, biological relatives, or other authorized recipients, it is wise for the statute to require that proof of identity be provided to ensure that the confidentiality of the information is maintained.<sup>476</sup>

#### b. Disclosure of Updated Information

Statutes that create a duty to update medical and social history vary significantly in their descriptions of the scope of the duty to transmit supplemental information. Some provide that supplemental information will be disclosed only upon request by an authorized recipient;<sup>477</sup> others

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473. One attorney recommends that, to protect child welfare agencies from liability, disclosure statements should contain an acknowledgment that the adoptive parents have received the information contained in the statement, that the forms be signed and dated by both the disclosing social worker and the adoptive parents, and that more than one social worker be present during the disclosure process as witness. Amadio, *supra* note 335, at 30; see also Meracle v. Children's Serv. Soc'y, 149 Wis. 2d 19, 23, 437 N.W.2d 532, 533 (1989) (describing "wrongful adoption" suit against private adoption agency for transmission of inaccurate medical information; dispute arose over the precise nature of the information that was provided).

474. Private agencies or private attorneys supplying information to prospective adoptive parents would, of course, account for the cost of investigating and disclosing information in their fee structure. Such statutes would thus be most applicable to disclosures to other persons, supplemental disclosures, and disclosures by governmental entities. See, e.g., ARK. CODE ANN. § 9-9-505(c) (Michie 1991) ("actual and reasonable cost of providing nonidentifying health history and genetic and social history shall be paid by the person requesting the information"); ARIZ. REV. STAT. ANN. § 8-129 (1989); TEX. FAM. CODE ANN. § 16.032(k) (West Supp. 1991).

475. See MICH. COMP. LAWS ANN. § 710.68(18) (West Supp. 1991) (fee of \$60 or the actual cost of supplying the information, whichever is less).

476. See TEX. FAM. CODE ANN. § 16.032(j) (West Supp. 1991) ("copy of the report may not be furnished to any person who cannot furnish satisfactory proof of identity and legal entitlement to receive a copy").

477. See ARIZ. REV. STAT. ANN. § 8-129(B)(3) (1989) (available on request); CONN. GEN. STAT. ANN. § 45a-746 (West Supp. 1991) (available on request); FLA. STAT. ANN. § 63.162(f) (West Supp. 1991) (furnished upon request); N.M. STAT. ANN. § 40-7-53(D) (Michie 1989) (available upon application to clerk of court); N.D. CENT. CODE § 14-15-16(3) (1991) (available upon request of adult adoptee); OHIO REV. CODE ANN. § 3107.17 (Anderson 1989) (may inspect upon request to clerk of court).

state that supplemental information should be furnished to adoptive parents automatically.<sup>478</sup> A third approach is to require affirmative steps by the agency to notify an adoptee or other authorized recipient only in life-threatening situations and to disclose supplemental information otherwise only upon request.<sup>479</sup> One state allows retention and release of supplemental information only upon court order following petition by the agency due to necessity for medical emergency or diagnosis.<sup>480</sup>

The transmission of supplemental information acquired after the initial investigation should not be limited to life-threatening emergencies. Information that may be relevant to future diagnosis or reproductive choices may not appear life-threatening, yet adoptive parents during the minority of the adoptee, the adult adoptee, and the adoptee's biological relatives and descendants all need access to the information. Thus, all supplemental information should be available on request to those statutorily approved for disclosure. To avoid the necessity of numerous requests to discover if information has been added, Ohio has developed a particularly useful mechanism whereby adoptive parents and others with a statutory right to access can file a single request to be notified of any supplemental information that is added to the records. When the addition is made, notification is forwarded automatically to the parents.<sup>481</sup>

Even with a good "continuing request" system, however, it is still important to place upon an agency, adoption intermediary, or the governmental agency serving as repository for the records, a duty to take affirmative steps to notify an adoptee or biological relative of medical or genetic information that threatens life or could seriously affect physical or mental health, or when a biologically-related person could give life-

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478. See MINN. STAT. ANN. § 259.47(2) (West Supp. 1992) (providing that agency must initiate contact to transmit information about a medical or genetic condition that could affect physical or mental health); *id.* § 259.253 (on consent of party agency will transmit nature of death or terminal illness of genetic parent or adoptee); TEX. FAM. CODE ANN. § 16.032(l) (West Supp. 1991) (supplemental information shall be furnished to adoptive parents); WIS. STAT. ANN. § 48.432 (West 1987) (health information generally available on request, but information on genetically transferred diseases automatically will be transmitted to adult adoptee or minor adoptee's adoptive parent).

479. See MICH. COMP. LAWS ANN. § 710.68 (West Supp. 1991).

480. See GA. CODE ANN. § 19-8-23 (Michie 1991).

481. See OHIO REV. CODE ANN. § 3107.17(E) (Anderson 1989). The form requesting notification of any correction or expansion of social and medical history information is filed with the permanent adoption records of the court clerk's office. The statute requires all investigators who prepared the initial report or the Department of Human Services to file with the court clerk any supplemental information supplied to them. When supplemental information is filed with the court clerk, the clerk then notifies anyone authorized for disclosure with a request form on file that additional information is on file and available for them to inspect. The statute further provides that when a final decree of adoption is filed, the court must give a request form, with an explanation of its purpose, to the adoptive parents. *Id.*

saving aid. Such circumstances obviously should not go without remedy simply because a request was not made for supplemental information. Another meritorious option is to require that the agency or some governmental entity forward all supplemental information to adoptive parents when it becomes available, rather than initiate a request system that gives the adoptive parent a choice about whether to seek it. While this system has much to recommend it, particularly the assurance of availability of information for future diagnosis, professionals caution that unexpected and unsolicited genetic information can throw an adoptive family into turmoil.<sup>482</sup> More extensive counseling involvement by social workers, however, beyond the simple conveyance of information, might help families cope with this stress.<sup>483</sup>

The need for sensitivity and counseling suggests the final aspect of transmission that must be considered—the mechanism for conveying supplemental information. Information that biological parents or relatives or adoptees will consider significant enough to add to the records will probably be serious. Conveying such information by mail is neither the most compassionate nor the most effective method of communicating anxiety-provoking news.<sup>484</sup> Such information should be communicated in person by a trained professional who can provide or refer the recipient to appropriate counseling.<sup>485</sup>

#### *F. Enforcement: Sanctions and Civil Liability*

Despite the good intentions of both state legislatures<sup>486</sup> and agencies<sup>487</sup> in embracing reform, significant pressures, both benevolent<sup>488</sup> and bureaucratic,<sup>489</sup> may cause individual workers, agencies, or other intermediaries to withhold or alter vital information. States therefore must consider imposing sanctions against government employees, agencies, or other intermediaries who fail to fulfill the statutory duty to investigate or disclose information properly. Noncompliance with the disclosure statutes should be a significant factor in the licensing evaluation of adoption agencies and should be grounds for disciplinary proceedings against pri-

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482. Black, *supra* note 85, at 199.

483. *Id.*

484. For example, Michigan requires that notice of life-threatening information be sent by first class mail to adoptive parents or an adult adoptee. MICH. COMP. LAWS ANN. § 710.68 (West Supp. 1991). First class mail provides no assurance that the message will be received, or that it will not be opened by others with no right to the information.

485. Black, *supra* note 85, at 199-200.

486. See *supra* note 177 and accompanying text.

487. See *supra* note 103 and accompanying text.

488. See *supra* text accompanying notes 81-83.

489. See *supra* notes 183-89 and accompanying text.



vate attorneys who handle independent adoptions. An additional possibility is to consider such violations as grounds for disciplinary action, including possible discharge for public employees.<sup>490</sup> As a last resort, criminal sanctions might be imposed upon agency personnel or professionals, acting as adoption intermediaries, who knowingly violate these statutes.<sup>491</sup>

The imposition of civil liability will probably continue to play a significant role in the enforcement of disclosure duties.<sup>492</sup> State legislatures therefore should either statutorily recognize a cause of action for persons harmed by inadequate disclosure or avoid imposing any statutory restrictions upon the recognition of such liability by the courts.<sup>493</sup>

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490. Cf. IND. CODE ANN. § 31-3-4-19 (Burns 1987) (outlining penalties for supplying false information to medical history, for disclosing information beyond authorization of statute, or for recklessly, knowingly, or intentionally allowing employee to commit such violations).

491. See IOWA CODE ANN. § 600.8(11) (West 1981) (establishing misdemeanor offense for "any person who assists in or impedes the placement or adoption of a minor person in violation of" the statutory requirements for placement, investigation, and disclosure of medical background information); LA. REV. STAT. ANN. § 9:422.13(D) (West 1991) (providing that failure to comply with provisions of disclosure of family history statute "shall be a breach of a fiduciary duty which shall be punishable by a fine of not less than one hundred dollars nor more than five hundred dollars"); see also UNIF. ADOPTION ACT § 10-e(c) (Tentative Draft 1990) (creating a misdemeanor for persons who knowingly fail to provide background information to prospective adoptive parents or who intentionally destroy such information); cf. IND. CODE ANN. § 31-3-4-19 (Burns 1987) (establishing class A misdemeanor for knowingly supplying false information to medical history, or recklessly or intentionally allowing an employer to do so).

492. For a list of several cases that have been instituted seeking damages for false or incomplete disclosure of health-related information in adoptions, see *supra* note 113.

493. Several of the recently enacted disclosure statutes include a limitation or preclusion of liability for disclosure made under the statutes. The intent of at least some of these provisions may be simply to clarify that disclosure of what would otherwise be confidential information creates no liability for breach of confidentiality or the right of privacy if it is within the scope of disclosure authorized by statute. Unfortunately, the language of some provisions appears broad enough to exclude liability for disclosure that is incomplete or inaccurate. See Act of September 27, 1983, ch. 1162, §§ 13-14, 1983 Cal. Stat. 4393, 4400 (not codified) (placing a maximum liability on the state or any licensed adoption agency of \$250 for damages caused by acts or omissions of their employers with regard to programs authorized by the act); ILL. ANN. STAT. ch. 40, para. 1522.5 (Smith-Hurd Supp. 1991) (no liability for "acts or efforts made within the scope of the act"). Others, while arguably applicable to intentional nondisclosure or misrepresentation, would appear to preclude liability for reckless or negligent incomplete, inaccurate, or unauthorized disclosure. See GA. CODE ANN. § 19-8-23(9) (Michie 1991) ("department employer or employee of any placement agency who releases information or makes authorized contacts in good faith and in compliance with this subsection shall be immune from civil or criminal liability for such release of information or authorized contacts"); N.D. CENT. CODE § 14-15-16(14) (1991) ("child-placing agency discharging in good faith its responsibilities under this section is immune from any liability, civil or criminal, that otherwise might result"); WIS. STAT. ANN. § 48.432(8) (West 1987) (civil and criminal immunity for persons who participate in good faith in the requirements of the disclosure statute).

The proposed discussion draft of the revised Uniform Adoption Act takes a better approach, stating simply that its criminal penalties for nondisclosure "do not preclude an adop-

## IV. CONCLUSION

Adopted children, their families, and their offspring have for many years paid a staggering price as a result of the policy of secrecy surrounding their medical history and social background. Failure to provide adequate information to adoptive parents has prevented adopted children from receiving critically needed psychiatric and medical care, so that many children suffered irreversible damage and many adoptive families were devastated. Their tragic experience has taught us that full disclosure of medical and social history of adopted children is essential to ensure that they receive appropriate medical and psychiatric care and to enhance their development of a personal sense of identity. Full initial disclosure and an effective mechanism to update information facilitates the diagnosis and treatment not only of the adoptee, but also of biological relatives and offspring who discover that they are at risk for certain disorders. Accurate transmission of information also allows adoptees and their biological relatives to make informed choices about their own childbearing.

Finally, complete disclosure of a child's medical and social history plays a vital role in placing a child with an adoptive family capable of meeting the child's special needs. Adoptive parents with realistic expectations and good preparation are far more likely to cope successfully with challenges. Moreover, the financial burdens of caring for a child with special needs can be lessened if parents have the information necessary to qualify for federal and state adoption assistance benefits.

In recent years the majority of state legislatures have responded to the disastrous effect of earlier adoption practices by enacting legislation requiring release of some background information. Nevertheless, most states still need significant reform to serve the goals of full disclosure adequately.

Disclosure statutes must be mandatory, their provisions must apply to all adoptions, and they should apply retroactively to those adopted prior to enactment of the statutes. They should require that information be disclosed not only to adoptive and prospective adoptive parents, but also to adult adoptees, their descendants, their biological family, and to unadopted adults whose parents' rights were terminated. To ensure that all necessary information is provided, statutes must be more specific in describing the content of the information to be collected and disclosed,

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tive parent or adoptee from bringing a common law action in tort against a person who negligently or intentionally fails to perform the duties required under" the sections regulating disclosure of background information. UNIF. ADOPTION ACT § 10-e(d) (Tentative Draft 1990).

which must include the medical and psychological history of the child, of the birth parents, and of other biological relatives, as well as the social and educational history of the child, of birth parents, and of ancestors.

More attention must be paid to the manner in which information is collected and stored. Responsibility for collection should rest with an agency or adoption intermediary and should be delegated only to trained professionals. A "reasonable efforts" requirement that would delineate the necessary collection efforts should be imposed by statute. These efforts should include conducting interviews with both birth parents and obtaining complete medical records of the child. If necessary, interviews also should be conducted with other family members, anyone who has had physical custody of the child, and medical personnel. Statutes should authorize medical-care providers and schools to release the child's records to the investigator. They should further authorize the release of medical records of a birth parent, under court order, if the information could significantly affect the child's health. The medical records of other biological relatives, however, should not be subject to disclosure without their consent, absent compelling circumstances. Such a wide exception to medical confidentiality would be an invasion of their right to privacy.

Many states have enacted statutes prohibiting the disclosure of information related to an individual's contraction of HIV or venereal diseases. A very limited exception to these statutes should allow courts to authorize disclosure of records indicating a birth mother's HIV status, but only when adequate information cannot be obtained from testing performed on the child. Such an exception is necessary to alert prospective adoptive families to the need to repeat testing and initiate medical treatment when appropriate.

"Reasonable efforts" frequently include an obligation to ensure that the child receives diagnostic testing. While conducting tests upon an infant may reveal personal information concerning the birth mother, such as HIV status or venereal disease, such testing is justifiable due to the importance of pursuing appropriate medical care for the child. Compelling birth parents or other relatives to submit to diagnostic testing, however, exceeds the bounds of appropriate investigation and invades their constitutionally protected right to privacy and bodily integrity.

Imposing sanctions through contempt or criminal proceedings upon birth parents who fail to provide complete information would be ineffective and would invade their privacy unnecessarily. Statutory provisions that protect confidentiality by prohibiting unauthorized disclosure and that establish use immunity in both criminal prosecution and civil suits would be far more effective.

Information must be collected and disclosed to prospective adoptive parents prior to a child's placement in their home, to facilitate informed decisionmaking on their part and to increase the chances for a successful placement. States also must create an effective system for collecting, retaining, and transmitting information relevant to hereditary disorders that surfaces after the initial investigation.

Much progress has been made since the days of total secrecy, when only caseworkers knew the facts about an adoptee's origins and pre-adoptive environment. To provide adoptees and their families the protection they deserve, however, states must reexamine their disclosure statutes to ensure that they are sufficiently comprehensive to meet the needs of all whose interests are affected, with due regard to the privacy interests of all concerned.

