Improving Access to Nonidentifying Medical Data in Florida Adoptions: A Call for Legislation

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Dan and Rhonda Stanton thought their adopted daughter, Stacey Rene, was the perfect baby because she didn’t cry. After several months, Stacey’s slow speech and motor development were tentatively diagnosed as Rett’s syndrome, a rare genetic disorder which halts brain growth. The Stantons returned Stacey to the agency. “We made a commitment to her, but we were not able to live up to that commitment,” says Rhonda. “She turned out to be totally different from what we thought we had adopted.”

In 1985, the Shoemakers adopted Monica, their eight-year-old foster child. As Monica grew, Mrs. Shoemaker witnessed her increasingly strange and frightening behavior. At one point, she

1. Andrea Sachs, When the Lullaby Ends: Should adoptive parents be able to return unwanted children?, TIME, June 4, 1990, at 82.
brandished a knife over Mrs. Shoemaker's chest; at another, she pressed a pillow to her baby sister's head while the family slept.

Social workers had not revealed Monica's family history to her adoptive parents. Information gathered from family members and juvenile court documents revealed that Monica's teenage schizophrenic mother had abused her sexually and physically, and that Monica's grandmother and great-grandmother both were mentally ill drug users. Monica was later diagnosed as schizophrenic also.²

I. INTRODUCTION

Today more than ever, physicians and geneticists realize the importance of heredity in health care.³ The family medical history of a patient is vital to the accurate diagnosis and treatment of many adverse health conditions.⁴ Without such information to guide the family physician, a patient may endure needless medical tests, pain, and expense.⁵

Unlike typical nonadopted persons, adoptees often lack access to their own family medical backgrounds.⁶ Because of a legislative history of secrecy surrounding adoption laws in the United States, many adoptees still know nothing about their biological families' medical histories.⁷ In most states today, adoption legislation has been revised to include statutory access to some information in the adoption record.⁸ Nonetheless, as recently as 1992, the adoption statutes of six states and the District of Columbia contained no provision for the

⁴ See Id.; see also Sarah Nugent, Commentary, The Release of Nonidentifying Information to Adopted Children: Striking a Balance Between the Rights of Biological Parents and Adopted Children, 23 RUTGERS L. REV. 709, 716 (1992). For the purposes of this Comment, the terms "medical information," "medical data," and "background" will include an individual's genetic and medical family history, as well as sociological data such as the existence of early childhood emotional trauma, abuse or neglect.
⁶ Lamport, supra note 3, at 109.
⁷ Id.
release of medical information to either adoptees or their adoptive parents.9

Chapter 63, Florida Statutes, governs adoptions in Florida. The state requires that adoptive parents receive general medical and social background information concerning the child before judgment of adoption, "when available."10 However, Florida's current statutory guidelines for the disclosure of nonidentifying genetic and social data are insufficient. Chapter 63 does not require adoption intermediaries to make an affirmative effort to secure any specific genetic or sociological data. Persons adopted before the disclosure of available medical data became mandatory may now request any medical information in their adoption files, but this process is slow and laden with paperwork. Several months usually pass before the requesting party receives any information.11

This Comment examines the reasons adoptees need to know their family medical histories. It explores practical issues surrounding the release of such information to adoptive parents, birth parents, and adoptees. It examines the current Florida adoption statutes as they relate to medical disclosure.12 Finally, this Comment builds on the current Florida adoption statutes to propose a modified scheme for more complete and simplified medical disclosure to adoptees and adoptive parents.13


10. Fla. Stat. §§ 63.022(2)(g); 63.082(3)(a), (b); 63.162(1)(f) (1993).


12. For the purposes of this Comment, the term "medical disclosure" means the release of nonidentifying medical, genetic, and social background information in the adoption record (or directly from birth parents) to adoptees or adoptive parents.

13. Five Senate bills and seven House bills dealing with adoption died either in committee or on calendar during the 1994 Florida legislative session. Fla. SB 264, 270, 404, 506, 2378 (1994), & Fla. HB 59, 139, 233, 607, 2491, 2539, 2819 (1994). These bills would have both broadened the inquiry into the adoptee's family background and guaranteed access to nonidentifying information. Fla. SB 404, Fla. HB 2491 (1994). The proposed bills, however, do not specify the type of information that adoption intermediaries must obtain from birth parents; neither do they facilitate access by cutting through procedure or notice provisions. These options are discussed in Part V of this Comment.
II. THE NEED FOR DISCLOSURE

In recent decades, physicians and geneticists alike have grown to understand that many diseases and disabilities are hereditary. Using information about a patient’s family medical history, doctors can now diagnose inheritable conditions with greater accuracy than they could a few years ago. Not only does a patient’s family history aid in identifying medical problems, it can also guide doctors in selecting the most suitable course of treatment for these problems. The benefits of a readily available medical history extend to the treatment of physical diseases and disorders as well as psychological, emotional, and behavioral problems.

A. Physical Disorders

The fact that individuals genetically transmit the propensity to develop many physical conditions is common knowledge. Diabetes, heart disease, and skin, lung, colorectal, ovarian, and breast cancers, to name but a few, are hereditary disorders. Although persons may be born with a high genetic risk for a particular disorder, early diagnosis can prevent some conditions from advancing or becoming fatal. Certain genetically linked disorders can be avoided altogether with early and accurate diagnosis.

Even when inherited diseases are inevitable and incurable, many individuals feel a pressing psychological need to know whether or not they carry the gene for particularly devastating conditions. One example is Huntington’s disease, a fatal neurological disease which usually manifests in mid-life. This incurable condition slowly cripples its victims, due to increased loss of muscle control over time. It eventually breaks down the central nervous system, causing delusions and mental deterioration.
A person with a biological parent who had Huntington's disease has a fifty percent chance of developing the disease.\textsuperscript{26} Researchers developed a direct gene test for the disease during late 1993 and early 1994.\textsuperscript{27} Although there is no cure for Huntington's, individuals with parents or siblings who have the disease often feel an urgent need to know whether or not they will also develop it.\textsuperscript{28} Because of the extremely debilitating nature of Huntington's, at-risk individuals may want to plan for the onset of the disease. But individuals will only be aware of their at-risk status if they have access to their family medical history. While many individuals may not want to know that they will develop such a devastating disease, others may feel a need to prepare themselves psychologically, financially, or otherwise, for the inevitable and frightening consequences of the disorder. Regardless of whether they are adopted or not, people should have access to information about their own biological propensity for such conditions. Without data about their own genetic risk, individuals often lack peace of mind and may live in a constant state of diffused anxiety about all dreaded hereditary diseases.\textsuperscript{29}

A comprehensive picture of an individual's medical background is also important for the practice of preventive medicine.\textsuperscript{30} If a person knows that he has a genetic predisposition to develop a disease, he will be able to watch for manifestations of the disease.\textsuperscript{31} He may also choose to take steps to stave off development of the condition by modifying his diet or avoiding certain behaviors.\textsuperscript{32} In the case of alcoholism, for example, doctors have recently found strong evidence of inheritability.\textsuperscript{33} Individuals who know that they have a family history of alcoholism often decide to drink only in strict moderation, or to abstain.\textsuperscript{34} The same logic applies to individuals who know they have a family history of heart disease, high blood pressure, or numerous other conditions which are to some degree preventable. Because medical information is so valuable for preventive purposes, adoptees and adoptive parents need easy access to complete and current genetic data concerning the birth family.

\textsuperscript{26} Id.
\textsuperscript{27} Telephone interview with Andrew McInnes, Huntington's Disease Society of America (Sept. 19, 1994).
\textsuperscript{28} 48 Hours, supra note 22.
\textsuperscript{29} Blair, supra note 5, at 709; Carolyn Burke, The Adult Adoptee's Constitutional Right to Know His Origins, 48 CAL. L. REV. 1196, 1202 (1975).
\textsuperscript{30} Nugent, supra note 4, at 716; Blair, supra note 5, at 705.
\textsuperscript{31} Nugent, supra note 4, at 716; Blair, supra note 5, at 705.
\textsuperscript{32} Nugent, supra note 4, at 716; Blair, supra note 5, at 705.
\textsuperscript{33} Blair, supra note 5, at 705.
\textsuperscript{34} Id. at 705 n.127.
Moreover, persons who know their family medical histories may weigh the known risks in deciding whether to have children of their own. Because certain conditions are known to skip a generation, to be passed from mother to son, or to occur among siblings, making a truly well-informed family-planning decision requires knowledge of whether one's biological family members have suffered hereditary disabilities. Would-be parents who know their own genetic backgrounds are free to evaluate the risks of inherited disorders for their unborn children. No one should lose this ability to make an educated decision simply by virtue of having been adopted.

Assessing a patient's family medical history is a basic part of medical care in the United States. Doctors routinely ask new patients to complete detailed medical history forms. Without adequate access to medical background information, adoptees and adoptive parents must leave many portions of these forms blank. This leaves the adoptee at a considerable disadvantage. Early and accurate diagnosis and treatment of medical disorders may be impossible without this information. Because it is fundamental to proper health care and to well-informed life choices, extensive medical background information must flow into the hands of adoptees and adoptive parents, unhindered by needless legal restrictions.

B. Psychological, Emotional, and Behavioral Disorders

Medical researchers know that certain psychological and emotional problems are genetically linked. The occurrence of manic-depression or schizophrenia in a person's biological relatives significantly increases that person's risk of developing the same disorder. For psychological disorders such as these, accurate diagnosis and early treatment are as critical as they are for physical diseases. To ensure complete and accurate diagnosis of any potential mental illness, adoptive parents need full disclosure of the emotional and psychological difficulties in their adopted child's birth family.

35. Lamport, supra note 3, at 109; Bebensee, supra note 8, at 398.
36. Blair, supra note 5, at 727 n.239, 737 n.291.
37. Id.
38. Id.
39. Id.
40. Lamport, supra note 3, at 109; Nugent supra note 4, at 715-16.
42. Blair, supra note 5, at 700-04.
43. Id.
44. Id.
Physicians and sociologists now also recognize that a child's early experiences strongly influence the development of behavior patterns. Children who suffer physical or sexual abuse, for example, often later exhibit violent or otherwise sociopathic behavior as a result. When the abuse or neglect is known, medical and psychiatric professionals can diagnose and treat resultant behavioral problems more successfully.

Furthermore, social workers report that it is better for an adoptee with special emotional or physical needs if prospective adoptive parents lacking the emotional or financial resources to rear such a child simply do not adopt that child. However, these special-needs children are not necessarily categorized as "unadoptable," because there are many couples who specifically wish to adopt an emotionally or physically challenged child and who are well-equipped to do so. Private and public placement agencies are experienced in matching special-needs children with suitable and loving homes. State adoption laws should not needlessly handicap couples willing and able to adopt special needs children; nor should they handicap special-needs children by hindering appropriate placement and thorough consideration of their extraordinary needs.

If the adoptive parents have advanced knowledge of the child's full genetic social history, they can begin preparing to meet such challenges. For these reasons, state adoption laws should specifically call upon adoption intermediaries to make affirmative efforts to discover any history of abuse, neglect, or genetically linked psychological disorders. Because the genetic and social history of adoptive children

45. Id.
46. Id.
47. Id.
48. Id. at 707; Janet Hopkins Dickson, Comment, The Emerging Rights of Adoptive Parents: Substance or Specter? 38 UCLA L. Rev. 917, 944-45, nn.144, & 149-51; see also Burr v. Board of County Comm'rs, 491 N.E.2d 1101, 1106 (Ohio 1986), in which the adoptive father of a child with Huntington's Disease stated on direct examination,

There is no way I can take care of this child. My wife's already crippled to start with. Am I going to take on another responsibility that I do not have right [sic] or the money and stuff to take care of this child? I can't handle a child like this ... I put my total trust and confidence in everything that the woman [the county agent] said. I didn't know that there was going to be a little child led up to my door with his medical records held back so that I couldn't doctor him.

49. There are waiting lists of prospective parents hoping to adopt special-needs children. Blair, supra note 5, at 707; Bebensee, supra note 8, at 397, 398; Interview with Helen Ervin, supra note 11.
50. Blair, supra note 5, at 707 n.140; interview with Helen Ervin, supra note 11.
51. There are commentators who have postulated that the disclosure of genetic background information will lead adoptive parents to search for the so-called "perfect baby."
has always been cloaked in privacy, practical changes in adoption laws can provide access to this crucial information.

III. THE ADOPTION PROCESS

The regulation of adoption began in the United States in 1850 when Texas and Vermont enacted the first general adoption statutes. The Massachusetts Adoption of Children Act of 1851 specifically called upon courts to aid in determining the suitability of prospective adoptive parents. This Act and similar public adoption laws led to a turn-of-the-century movement establishing the "best interests of the child" as the governing standard in adoption law. Ostensibly, this standard continues to control modern adoption law in the United States and is the basis of the current adoption process.

In most states, including Florida, individuals who want to adopt a child may choose from three types of legal intermediaries. Prospective parents may adopt through (1) a state agency, (2) a private agency, or (3) an independent intermediary. In Florida, the Depart-
ment of Health and Rehabilitative Services (HRS) is the state agency that oversees adoptions and licenses private adoption agencies.

A. Agency Adoptions

The agency adoption process in Florida is fairly straightforward; the same statutes govern private and public agencies. Usually, the birth parents will contact an agency to arrange for placement during the pregnancy. Before the search for a suitable adoptive home begins, public and private agencies in Florida counsel the birth mother about the adoption process and the decision to give up her child. After preliminary counseling, the agency begins gathering general information from the birth mother and, once the child is born, secures her written consent to the adoption.

Florida statutes specifically require that the biological family medical history not contain any names or identifying information. Florida also mandates that, before the adoption becomes final, adoptive parents receive the general medical information required by the standard state-issued medical forms, “when [such data is] available.” The data and consent forms become part of the adoption record, which is kept on file at a central location.

Florida also requires that the agency conduct a preliminary home study to determine the suitability of a prospective adoptive couple to parent a particular child. The agency interviews the intended adoptive parents and evaluates their financial security and the physical environment of their home. The home study includes a records check of the central abuse registry of HRS and a statewide criminal records correspondence check of the prospective adoptive parents. If the home study is favorable, the agency will place the child in the home.

59. Interview with Helen Ervin, supra note 11.
61. See Fla. Stat. § 63.082(3), (4) (1993); This counseling, consent, and information-gathering will also include the birth father if he is reachable. Bills which were proposed and died in the last legislative session would have significantly impacted paternal rights and instituted a paternity registry. Fla. HB 139, 2491 (1994). Interview with Helen Ervin, supra note 11.
63. Id.
64. Id.
65. Interview with Helen Ervin, supra note 11.
67. Id.
68. Id.
69. Id. § 63.092(2); interview with Helen Ervin, supra note 11; see Bebensee, supra note 8, at 400.
Once the adoptive parents file a petition for adoption, a judge examines all the information then in the record and, if all is satisfactory, grants the petition and issues a judgment of adoption. All records of these proceedings become confidential.70 Adoptive parents who do not want to adopt through an agency may choose an independent intermediary, usually an attorney or other professional.71

B. Independent Intermediary Adoptions

In Florida, independent adoptions follow essentially the same procedure as do agency adoptions.72 Independent intermediaries (licensed attorneys or physicians) must complete the same requirements for the judgment of adoption as a licensed agency.73 Independent intermediaries often enlist the help of an agency in completing the requirements for legal adoption.74 For example, they may request that a private agency conduct the preliminary home study and prepare the accompanying report and recommendation.75 Once the court issues the final decree, the independent intermediary keeps the sealed adoption record on file in his office.76

IV. Adoption Statutes and Medical Disclosure

A. Historical Overview

For decades, the prevailing public policy on adoption in the United States was one of uncompromising secrecy.77 This policy was an outgrowth of the “best interests of the child” standard in adoption laws.78 Legislators believed that the law would shield the adoptee from the stigma attached to adoption and illegitimacy.79 Thus, they rea-

70. FLA. STAT. §§63.142, 63.162(1)(b) (1993).
71. Interview with Helen Ervin, supra note 11.
72. Bebensee, supra note 8, at 400-01; FLA. STAT. § 63.092 (1993); interview with Helen Ervin, supra note 11.
73. FLA. STAT. § 63.092 (1993); see also Bebensee, supra note 8, at 402 (noting that in other states, clergy, psychologists, and other professionals may be licensed intermediaries).
74. Interview with Helen Ervin, supra note 11.
75. Id.; see also Bebensee, supra note 8, at 409 n.113 (citing Dickson, supra note 48, at 939-40).
76. Interview with Helen Ervin, supra note 11; FLA. STAT. § 63.162 (1993).
77. Lamport, supra note 3, at 110-11.
soned that keeping the birth family’s medical information from the adoptee protected and served the adoptee’s best interests.80

But legislators also had another purpose in mind when they drafted adoption statutes. The primary objective of all states in regulating adoption was to promote the adoption process.81 By ensuring birth mothers that no one would ever know their identities, legislators believed they were encouraging these women to choose adoption.82 This objective is still a primary justification for keeping identifying data in the adoption record confidential.83

For these reasons, adoption statutes prohibited access to any information contained in the adoption record, including medical background information. This blanket barrier to medical disclosure resulted because the state legislatures did not distinguish between identifying and nonidentifying information about the birth family.84 Nonidentifying medical history remained hidden with identifying information in the adoptee’s record.85

Slowly, state legislatures have begun to recognize the importance of medical and social information and have distinguished medical data in the record from identifying information.86 Consequently, adoptees in the United States today may receive summaries of their own genetic and social background without learning the names of biological family members.

Florida’s adoption laws distinguish between identifying and nonidentifying information.87 The statutes specifically state that medical

80. Nugent, supra note 4, at 712; see, e.g., In re Spinks, 232 S.E.2d 479, 482 (N.C. Ct. App. 1977) (reasoning that confidentiality protects the child’s adoptive family from interference and helps the adoptee identify with his new family, so that disclosure would rarely serve the child’s best interests).

81. Nugent, supra note 4, at 712; Tartanella, supra note 78, at 471.

82. Some lawmakers postulate that if a birth mother believes there is a chance that her family or others will discover that she had the child, she will forego adoption and choose abortion instead. They also reason that withholding the biological parents’ identity will encourage prospective adoptive parents to adopt. The assumption is that adoptive parents fear their child will someday reunite with his natural parents and that they will lose the child’s affection. By barring the adoptee’s access to the birth parents’ identities, so the theory goes, the state alleviates these fears. Alma Society, 601 F.2d at 1235; Tartanella, supra note 78, at 758. But see Burke, supra note 29, at 1211.

83. Tartanella, supra note 78.

84. "Nonidentifying" information includes any facts that will not lead to the discovery of the birth parents’ identity. This may include details about the birth parents’ genealogical, medical, personal or social backgrounds. Nugent, supra note 4, at 711 n.7.

85. Not until the early 1980’s did state legislatures begin revising their adoption laws to allow access to medical information. Interview with Helen Ervin, supra note 11.

86. Nugent, supra note 4, at 716-18; Bebensee, supra note 8, at 403-04; FLA. STAT. § 63.162(1)(f) (1993).

87. FLA. STAT. § 63.162(1)(d), (f) (1993).
data gathered from the birth parents and included in the adoption record must not contain any identifying information.\textsuperscript{88} This separation of the two types of information makes medical disclosure a potentially simple matter. It virtually eliminates any danger that release of the family history to the adoptive parents or child will deter adoptions.

The fact that Florida distinguishes between identifying and non-identifying information in its adoption laws indicates that the state is interested in protecting the adoptee as well as the adoptive process. Indeed, this type of legislation serves the best interests of the adopted child far better than did the historically broad policy of secrecy. However, this distinction is only a first step. The statute should be improved and refined so that adoptees and adoptive parents can more easily obtain additional vital medical background information. The statute allows room for improvement in the types of data collected and the methods of collection and disclosure.

B. The Florida Adoption Statutes

Sections 63.022, 63.082, and 63.162, \textit{Florida Statutes}, concern medical and social information in the adoption record. Section 63.022(2)(g) generally provides for the collection of social and medical information about the adoptee and the natural parents to safeguard the welfare of all members of the adoption triad.\textsuperscript{89} Upon the child’s placement, the data becomes part of the adoption record together with the consent forms.\textsuperscript{90} Section 63.082(3)(a) provides that birth parents intending to place a child for adoption must complete family medical history forms. The section leaves the determination of the type of information required by these forms to the discretion of HRS.\textsuperscript{91} The medical data required by the forms may, and does, include biological and sociological information.\textsuperscript{92}

Intermediaries gather readily available information about the natural mother and father, maternal and paternal grandparents, aunts, and uncles.\textsuperscript{93} The medical history forms also request developmental data concerning any siblings or half-siblings of the adopted child.\textsuperscript{94} But the statute requires that birth parents complete this form only to the extent that the data requested is “available or readily obtaina-

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\item 88. \textit{Id.} § 63.162(1)(f).
\item 89. The “adoption triad” includes the adoptee, the adoptive parents, and the birth parents.
\item 90. Official consent forms must be executed by the birth parents and filed together with the petition for adoption. \textit{Fla. Stat.} § 63.082(1)-(2), (3)(b), (4) (1993).
\item 91. \textit{Id.} § 63.082(3)(a).
\item 92. \textit{Id.}; A copy of this form, labeled “Appendix,” is included at the end of this Comment.
\item 93. \textit{See} Appendix \textit{infra}; interview with Helen Ervin, \textit{supra} note 11.
\item 94. \textit{See} Appendix \textit{infra}.
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ble. The statute neither imposes a duty on the part of intermediaries to take affirmative steps to collect any specific data, nor requires any medical testing to complete the form.

Section 63.162 mandates the confidentiality of all adoption records, whether they are kept by the court, HRS, an adoption agency, or an independent intermediary. Under this section, adoption hearings are held in closed court, and all records of the court proceedings are confidential. Section 63.162(1)(f) makes an exception for nonidentifying information. Before the adoption becomes final, the adoptive parents must receive any available social and medical history without any names or identifying information. This notable provision protects the interests of both the child and the adoptive parents by providing the adoptive parents with notice of any potential or actual medical or behavioral problems the child may have before they legally adopt. A couple may choose not to adopt a child whom they believe they are unable to rear. The child may then be adopted by a family that is equipped to provide the necessary care. In this context, early and complete medical disclosure allows a better match between adoptive parent and child.

Section 63.162(1)(f) further provides that the adoptive parents may request and are entitled to receive any nonidentifying information added to the record after the adoption is complete. This is another important provision of the Florida adoption statutes because, although there may be no known medical difficulties within the birth family at the time of adoption, family members may later report serious problems. Timely access to updated information is essential, because parents operating with an incomplete or possibly incorrect medical history risk making poor decisions regarding the medical treatment or daily lifestyle of their adopted child.

Finally, once the adoptee reaches the age of majority, section 63.162 provides that he becomes legally entitled to receive his family medical and social history from the adoption record. However, the

96. In fact, mandatory testing for sickle-cell trait (sickle-cell anemia is a potentially fatal genetic condition) is specifically prohibited as a condition of eligibility for adoption. Id. § 63.043.
97. Id. § 63.162(1)(b).
98. Id. § 63.162(1)(a), (b).
99. Id. § 63.162(1)(f).
100. Id.
101. The Children's Home Society reports that adoptive parents and birth parents alike frequently contact the agency with new medical information about themselves, the adoptee, or another relative, so that all parties who can benefit from the new information receive it.
adoptee must file a written request for this information, and such a request generally takes from six to eight months to process.\textsuperscript{103}

The Children's Home Society (CHS) provides an efficient model for the transmission of information from the birth family to the adoptive parents. For instance, if the biological grandmother of a female adoptee develops breast cancer, she or the biological mother may contact CHS with that information. A CHS counselor will then contact the adoptive parents by mail to alert them that they should call or come by the CHS office. The counselor will tell the adoptive parents that the natural grandmother has developed breast cancer. Any other medical details provided will also be communicated, without any names or other identifying information.\textsuperscript{104}

Often, new medical information has the potential to be disturbing or frightening to adoptive parents. Through counseling, CHS ensures that the parents have a proper perspective on what the information actually means to the child's health.\textsuperscript{105} In the example above, the CHS counselor could dispel exaggerated fears by explaining the significance of breast cancer and the increased risk to the child of developing it. CHS counselors also provide guidance to the adoptive parents in contacting a physician for advice about using this information to the child's advantage. A physician can educate parents about monitoring their child for breast cancer as she grows older, and taking appropriate preventive steps.\textsuperscript{106}

Adoptive parents with an inadequate grasp of the meaning and impact of new medical information can become frantic. Personal counseling gives them the information and perspective necessary to help them and their child assimilate the new information without inflated fears. A parent who receives thorough counseling can make the proper health-care decisions for the child. The state has a strong interest in every child's health, safety and welfare, and an informed and calm parent is the best assurance of this goal.

\textsuperscript{103} Interview with Helen Ervin, \textit{supra} note 11. In cases where the need for information is particularly urgent, CHS expedites the request by giving it priority over other requests on file. \textit{Id.}

\textsuperscript{104} \textit{Id.} The birth mother is not the only person who takes the initiative in these circumstances. It is not uncommon for the person who has the medical condition to be the one who contacts CHS. \textit{Id.} In this example, the natural grandmother herself might contact CHS.\textsuperscript{105}

\textsuperscript{105} \textit{Id.}

\textsuperscript{106} One adult adoptee who discovered that she had a family history of fibrous breast lumps managed to avoid painful treatments she would have otherwise had to endure for proper diagnosis. Blair, \textit{supra} note 5, at 704 n.120 (citing Ginny Whitehouse, \textit{Remarks in Panel Discussion at Conference on Genetic Family History: An Aid to Better Health of Adoptive Children}, in \textit{Wisconsin Clinical Genetic Ctr. & Waismann Ctr. on Mental Retardation & Human Development, Genetic Family History: An Aid To Better Health Of Adoptive Children} 26 (Nat'l. Ctr. for Educ. in Maternal & Child Health ed., 1984) [hereinafter \textit{Genetic Family History}]).
Section 382.027, *Florida Statutes*, establishes a voluntary registry of adoption information. This section is actually a part of the Public Health title's vital statistics chapter, and not part of the adoption chapter itself. The registry contains only identifying information, such as names and addresses, concerning the adoptee and the birth parents. This provision implicitly acknowledges the significant difference between data that can lead to identification of parties to the adoption and that which does not. This acknowledgment is pivotal because it preserves the identities of individuals who wish to remain anonymous, while allowing the release of other vital information to adoptees and adoptive parents.

While the Florida adoption statutes recognize the practical differences between identifying and nonidentifying information, the statutory scheme for medical disclosure remains inadequate. Administrative requirements slow the process of receiving medical information after the adoption. Also, the statute too loosely delineates the type of information to be gathered from the birth parents, and the methods of collecting it. And while the statute requires that parties to both public and private adoptions receive counseling about adoption generally, it sets forth no specific guidelines regarding this service. The following are suggestions for improving current Florida laws in these key areas.

V. IMPROVING THE FLOW OF INFORMATION ACROSS THE ADOPTION TRIAD

A. Type of Information Collected Before Adoption

Because of the fundamental importance and increasing utility of social and genetic background information, the law should provide

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108. The registry contains the "last known names and addresses of an adoptee and his natural parents and adoptive parents and any other identifying information which the adoptee, natural parents, or adoptive parents desire to include in the registry." *Fla. Stat.* § 382.027 (1993). While not requiring any person to enter information in the registry, section 382.027 allows any individual who wishes to update data in the registry to do so at will. *Id.*

109. All states which specifically allow disclosure of medical background information to adoptees or adoptive parents mandate that the information be purged to protect the identities of biological relatives. Bebensee, *supra* note 8, at 399 n.25.

110. The statute restricts the list of persons who may retrieve information contained in the registry. At most, the adoptee, the natural parents, adoptive parents, natural siblings, and natural grandparents may access the information contained in any one file in the registry. No one else may retrieve information from the registry, and anyone who enters information in the registry may limit access to that particular piece of information even further if he wishes. In the absence of the entrant's consent, the persons seeking access to registry information must obtain a court order to do so. *Fla. Stat.* § 382.027(1) (1993).

111. *Id.* § 63.092(2)(e).
adoptees and adoptive parents unhindered access to such data. The state can improve access by expanding the type of information intermediaries collect prior to adoption. Presently, the statute provides for the collection of only general medical data, leaving to HRS discretion as to what specific facts intermediaries must gather.\textsuperscript{112}

The current HRS medical information form does include several types of medical information, but it excludes other categories of information. The Florida Legislature should statutorily mandate the collection of more specific information about the birth parents before adoption. While it would be impractical for the statutes to list every conceivable piece of medical information that could have a hereditary impact, the statutes should be more exhaustive to ensure that intermediaries gather key genetic and sociological data.\textsuperscript{113}

The statute should specifically mandate that genetic data be collected from the birth family. Because many conditions are transmitted chromosomally without manifesting themselves in every generation, a simple account of medical disorders actually experienced by the birth mother and father may be misleading.\textsuperscript{114} Patterns of inheritance vary from disorder to disorder, sometimes skipping a generation and sometimes occurring frequently in sibling groups.\textsuperscript{115}

In 1991, the American Society of Human Genetics issued a report urging that "every person should have the right to gain access to his or her medical record, including genetic data," and that medical files of all adoptees should routinely include genetic history.\textsuperscript{116} Providing a medical history with a truly genetic component means extending the scope of the history to include information beyond the medical conditions of the birth parents.

\textsuperscript{112} Id. § 63.082(3)(a) (providing that the medical history form filed with the petition for adoption contain "such biological and sociological information, or such information as to the family medical history, regarding the child and the birth parents as is required by [HRS]").

\textsuperscript{113} The Golden Cradle adoption agency, in Cherry Hill, N.J., requires natural mothers to fill out ten-page histories that ask about everything from hay fever and heavy drinking to Down's syndrome and blood transfusions. Genetic counselors are often called in as consultants. 'We believe an ounce of prevention is worth a pound of cure,' says agency supervisor Mary Anne Giello.

\textsuperscript{114} Id. at 736-37

\textsuperscript{115} Id. at 737 n.291 (citing Catherine A. Reiser, \textit{Basic Principles of Genetics: A Human Approach, in Genetic Family History, supra note 106}).

\textsuperscript{116} \textit{American Society of Human Genetics, American Society of Human Genetics Social Issues Committee Report on Genetics and Adoption; Points to Consider}, 48 \textit{Am. J. Hum. Genetics} 1009, 1009-10 (1991) [hereinafter \textit{Report on Genetics and Adoption}]; Blair, supra note 5, at 736-37.
The current HRS form records the specific physical conditions of the birth parents, maternal and paternal grandparents, and siblings of the birth mother and father. However, only limited information about other children of the natural parents is recorded. This part of the form asks the ages and sex of the siblings; their relationship (half or full sibling) to the adoptee; whether the sibling was prematurely born; and the ages at which the sibling began walking and talking. The statutes should require that intermediaries gather the same information about the adoptee's siblings as they do for the other members of the extended family, in addition to the information currently gathered. Because siblings are genetically the closest of relatives, this would provide a more complete and accurate genetic history.

The form provides little space for documenting mental or emotional problems in the birth family. The statute should specifically require a more extensive inquiry into this area. Because psychological and emotional disorders are often hereditary, the statutes should require complete information about psychological difficulties experienced by the birth parents, grandparents, siblings, aunts or uncles.

In the interest of the proper placement of special-needs children, the statute also should require that the medical forms request information regarding any psychological or emotional difficulties the adoptee himself has experienced. Abused or neglected children may not exhibit psychological and behavioral difficulties for several years. Well-meaning birth parents or a guardian may be unaware of the probability that the child will develop behavioral or emotional problems as a result of such difficulties. They also may not realize that adoptive homes for abused children are plentiful. Therefore, the state should mandate the collection of specific facts concerning abuse, neglect or other trauma in the adoptee's past to better ensure proper placement of special-needs children.

The training of all adoption intermediary counselors to ensure that birth parents understand the implications of abuse or neglect in a child's past is equally important. The state should then require that these trained facilitators educate all birth parents about the importance of revealing such information for the child's welfare and suc-

117. See Appendix infra.
118. Id.
119. Id.
120. This type of problem can be particularly complex and may go unrecognized by lay persons. Moreover, counselors may not adequately explain this category of disorders to the birth parents.
121. See supra notes 42-51 and accompanying text.
122. See supra notes 48-51 and accompanying text.
cessful placement. Counselors should stress to birth parents that this sensitive data will not be attached to any identifying information.

The current HRS adoptee information form does not include a space for recording information about a family history of alcoholism or drug addiction. The statute should specifically require inquiry into substance abuse because of the inheritability of such tendencies. This information should be collected from all family members from whom other information is taken.

It is especially important to gather information about the birth mother's use or abuse of alcohol or prescription or illegal drugs during pregnancy. Use of such substances during pregnancy can cause prenatal drug addiction, fetal alcohol syndrome, and other disorders in the unborn child.\(^1\) The statute should specify that substance abuse information be collected on all extended family members, with special attention to securing such data concerning the pregnant mother. While the Legislature need not attempt to include an exhaustive list in the statute, expanding the statute to require collection of the above information will help to ensure that the family medical history the adoptive parents receive before adoption is more complete, useful, and meaningful.

Finally, the statute should eliminate the vague language requiring that medical history forms contain only data which is "available or readily attainable." The Legislature should mandate that intermediaries make affirmative efforts to discover extensive medical data. Requiring intermediaries to use reasonable or good-faith efforts in the collection of medical and sociological information will help to eliminate the problem of workers who avoid pursuing sensitive problems.\(^2\)

### B. Medical Information Registry

The lack of an automatic mechanism releasing new medical and social information after adoption creates a delay which is unnecessary if such data has been stripped of names and other identifying information. Currently, adoptive parents must request medical updates to receive new information. Paradoxically, the statute recognizes the vital nature of family medical history in its requirement that adoptive parents automatically receive all genetic data available before adoption. The fundamental nature of such data should require that adoptive parents also automatically receive any new or updated medical information about their child.

\(^{123}\) Bebensee, *supra* note 8, at 398 n.16 (citing Dickson, *supra* note 48, at 943-44).

\(^{124}\) *Id.* at 409 n.113 (citing Dickson, *supra* note 48, at 951 n.12).
Florida law already establishes a voluntary registry of identifying adoption information. The state should now create a registry of nonidentifying medical information. This registry should contain all medical information gathered both before and after adoption which is already in the adoptee's file. The registry should allow any qualified person who wishes to add or correct facts in a file to do so.

However, the state need not impose an actionable legal duty on any member of the birth or adoptive family to come forward with new medical data for the registry. Such a duty would reach too far into privacy interests and would be difficult, if not impossible, to enforce. Even the American Society of Human Genetics, in advocating the routine inclusion of genetic history in every adoptee's medical files, conceded that the "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." One commentator has noted the probability that the publicity from such enforcement proceedings may deter biological parents from considering legal adoption.

Skilled, professional counseling concerning the need for complete medical information, along with reassurance that the data will be stripped of all identifying details, should elicit candor from birth parents. The Children's Home Society of Florida, which counsels its clients on the importance of updating medical history records, reports that birth parents and adoptive family members voluntarily contact CHS with new medical data frequently.

Nor should the Legislature mandate medical testing of birth or adoptive parents, either before or after adoption. Recently, the National Conference of Commissioners on Uniform State Laws considered revising the Uniform Adoption Act to require blood testing and DNA profiles of biological parents. The revision, which the com-

126. The law recognizes a federal constitutional privacy interest which has been defined to include the freedom to control one's bodily integrity. Eisenstadt v. Baird, 405 U.S. 438 (1972); Blair, supra note 5 at 688, nn.38-39 (citing Whalen v. Roe, 429 U.S. 589, 600 (1977) (recognizing a federal constitutional privacy interest in "avoiding disclosure of personal matters"); Griswold v. Connecticut, 381 U.S. 479 (1965).
127. See supra note 116 and accompanying text.
128. Blair, supra note 5, at 763 n.422 (citing Report on Genetics and Adoption, supra note 116).
129. Id. at 763-64.
130. Interview with Helen Ervin, supra note 11.
131. Blair, supra note 5, at 760 n.410, 685 n.16 (citing a telephone interview with Joan Hollinger, Reporter to the National Conference of Commissioners on Uniform State Laws on the Uniform Adoption Act (Nov. 5, 1990)).
mittee did not pass, would have provided for sanctions against biological parents who refused to comply.\textsuperscript{132}

Forced medical screening would implicate the privacy interests of the tested individual, whereas the duty to add to a non-identifying medical information registry would maintain an individual's privacy interests.\textsuperscript{133} The right to refuse medical treatment and the right of bodily integrity are judicially-recognized components of the right to privacy, under both the common law and federal Constitution.\textsuperscript{134} The right to refuse forced testing would logically fall into the recognized right to privacy.

Rather than taking the extreme measure of requiring medical testing by statute, the state should rely upon thorough counseling and education provided by professionals to all parties involved in the adoption process. Careful explanation of the vital nature of medical information and the need to keep that information current should encourage most triad members to provide accurate information and to supplement the registry voluntarily.

One notable exception to this idea is Human Immunodeficiency Virus (HIV). A child cannot become infected with HIV genetically, and there is no evidence that an infected father can cause perinatal transmission.\textsuperscript{135} However, an infected mother can transmit HIV to her child in utero.\textsuperscript{136} She can also transmit HIV to her baby through breast feeding or during the birth of the child.\textsuperscript{137} In Florida, no law mandates HIV testing of pregnant mothers intending to give a child up for adoption. Section 381.004 (3)(f)(11) mandates that, if the intermediary or birth parent knows that the child is infected with HIV, he must inform the prospective adoptive parents of that fact.

Some private agencies require all birth mothers to undergo HIV testing prior to adoption as a policy matter.\textsuperscript{138} Others require HIV testing only of those mothers considered to be at high risk for infection.\textsuperscript{139} CHS requires testing of all birth mothers, but does not require

\begin{itemize}
\item \textsuperscript{132} Id.
\item \textsuperscript{133} See supra notes 126-29 and accompanying text.
\item \textsuperscript{134} See, e.g., In re A.C., 573 A.2d 1235, 1243-47 (D.C. App. 1990); United States v. Charters, 829 F.2d 479, 490-91 & nn.18-19 (4th Cir. 1987); Blair, supra note 5, at 688, 760.
\item \textsuperscript{135} Blair, supra note 5, at 753.
\item \textsuperscript{136} Id. at 754 (citing S. Sheppard, Medical and Public Health Overview of HIV Infection, in AIDS Practice Manual, at 2-9 to 2-14 (Paul Albert et al. eds., 3d ed. 1991).
\item \textsuperscript{137} Id.
\item \textsuperscript{138} Id. at 759-60 & n.409 (citing NATIONAL COMMITTEE FOR ADOPTION, 1989 ADOPTION FACTBOOK 131 (1989)).
\item \textsuperscript{139} Id.
\end{itemize}
that birth mothers reveal the results of the test to the agency. Instead, CHS informs the birth mother that revealing such information is vital to her baby's health.

The Legislature must carefully consider the privacy implications of any law that would require mandatory HIV testing of birth mothers. Mandatory testing would certainly invade the right of bodily integrity of the mother, but because of the critical and epidemic nature of AIDS, a state's interest may override that privacy interest in this case. The state has an interest not only in preventing the spread of AIDS, but also in providing the most suitable home for HIV-positive adoptive children. Requiring testing of the birth mother would allow intermediaries to locate adoptive homes specifically prepared to care for HIV-positive babies. CHS reports that there are more than enough adoptive homes able and specifically wishing to adopt HIV-positive babies in Florida. Mandatory screening for HIV in birth mothers would be a positive addition to the current Florida adoption statute.

C. Disclosure Mechanism

A registry of nonidentifying medical data will allow the Legislature to create a more efficient mechanism for disclosure of new medical information. Rather than requiring requests for new information, the state should assume that all parties to the adoption will want this vital data. The state should provide for automatic notice by mail of any updates in the records to adoptive parents, birth parents, and adoptees.

It is important, however, that the registry operate in both directions: information should flow from adoptive parents and child to birth parents, as well as from birth parents to the adoptive parents and child. This mutuality allows the birth parents access to valuable health-related information which may impact their own life choices in much the same way as it does for adoptees. As long as the medical information remains non-identifying, it is possible to allow its free exchange among members of the adoption triad.

140. Interview with Helen Ervin, supra note 11; The identity of any person upon whom an HIV test has been performed and the test results are confidential. Fla. Stat. § 381.004(3)(f) (1993).
141. Interview with Helen Ervin, supra note 11.
142. See supra notes 126-29 and accompanying text.
143. Florida's constitutional privacy provision would likely prevent mandatory testing by the state. Fla. Const. art. I, § 23. However, testing by independent agencies and strict confidence might overcome the birth parent's fears.
144. Interview with Helen Ervin, supra note 11.
In the event that updated information is of a serious nature, it should be disclosed to members of the triad by a trained professional. The state’s notification letter should reveal information which is not of an alarming nature. Counseling will help the recipient cope with sensitive information, and could be conducted by physicians, psychologists, or social workers at private adoption agencies (such as CHS) who currently provide this service to their own clients. Regardless of which professionals the state chooses as qualified counselors, the service must be provided in state agency adoptions. The state must also mandate that private agencies and intermediaries provide such counseling if they do not already. The state has a substantial interest in the emotional well-being of the recipients of alarming information, and proper delivery of such news is indispensable to that goal.

D. Automatic Disclosure to the Adult Adoptee

The current Florida statute allows the adoptee to receive nonidentifying medical and social information from his adoption records upon reaching age eighteen. However, the adoptee must request the information and usually wait several months before receiving it; this delay is largely attributable to the high number of requests intermediaries must process.

Automatic disclosure would streamline the disclosure process. The system would reduce administrative backlog by eliminating the processing of written requests. At age eighteen, adoptees would automatically receive a copy of all non-identifying social and medical information that they have not already obtained. As with the proposed medical registry, the adoptee would not receive disturbing medical information without counseling. This counseling may come from qualified registry counselors or, in the case of private agency adoptions which already provide such services, through the private agency’s own counselors. Files free of alarming data would be released directly to the adoptee. Several weeks prior to the adoptee’s eighteenth birthday, the state should mail notice to the adoptee that he will soon receive, or be entitled to receive, his medical history records.

Since triad members may be unaware of their rights under the changing laws, the state should also provide general notice that a voluntary

145. Face-to-face counseling is required for all individuals who are receiving the results, positive or negative, of an HIV test. Fla. Stat. § 381.004(3)(c) (1993).
146. Interview with Helen Ervin, supra note 11.
148. Id.
149. Interview with Helen Ervin, supra note 11.
registry exists and that both birth and adoptive families have access to it. Although the state is not obligated to inform citizens of all of their rights under its laws, the importance of access to one's own genetic and social background for health and welfare reasons warrants public education efforts. Public service announcements on radio, on television, or in print, are the best way to accomplish this task.

VI. CONCLUSION

Genetic and sociological information is becoming increasingly vital to proper health care. Although medical advances in this area have occurred rapidly for several decades, adoption law has not kept pace with these advances. With the implementation of the legislative proposals suggested in this Comment, the State of Florida has the opportunity to align its laws more closely with the modern state of medicine and health care. Perhaps more significantly, the state has the opportunity to recognize more meaningfully the fundamental rights and needs of Floridians who have become a part of the unique experience of adoption. The proposals made in this Comment will not guarantee the availability of more information for members of the adoption triad, but they will provide a greater opportunity for disclosure of crucial medical and family history to adoptees and their biological and adoptive parents. Such an opportunity will be an improvement over today's adoption mechanism in Florida.
## APPENDIX

**FAMILY, SOCIAL AND MEDICAL HISTORY OF CHILD TO BE ADOPTED**

### BIRTH MOTHER

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<th>Race/Nationality</th>
<th>Reason for Placing Child</th>
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<tr>
<th>Color of Hair</th>
<th>Height of Mother</th>
<th>Weight of Mother</th>
<th>Complexion</th>
<th>Build</th>
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</thead>
<tbody>
<tr>
<td>Type of Features</td>
<td>Color of Eyes</td>
<td>Was Pregnancy Normal?</td>
<td>Was Delivery Normal?</td>
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<td></td>
<td></td>
<td>Yes</td>
<td>No</td>
<td>Explain</td>
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- Any Medication or Drugs Taken During Pregnancy? (If "yes," explain or list drugs)
  - Yes
  - No

- Alcohol Consumption During Pregnancy?
  - Yes
  - No
  - Unknown

### FAMILY HISTORY (MATERNAL)

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<thead>
<tr>
<th>Birth</th>
<th>Child's Grandmother</th>
<th>Child's Grandfather</th>
<th>Mother's Sibling #1</th>
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<th>Mother's Sibling #3</th>
<th>Mother's Sibling #4</th>
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<td>Religion</td>
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<td>Occupation</td>
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<td>Died or Deceased</td>
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<tr>
<td>If Deceased, List Cause</td>
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### PHYSICAL CONDITION (Check if applicable. If applicable, attach additional sheet to explain.)

- Heart Disease
- Cancer
- Diabetes
- Hypertension
- Orthopedic
- Vision
- Hearing
- Dental History

* Continue on Attached Sheet, if necessary
# 1994 FLORIDA ADOPTIONS

## PATERNAL

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<th>Color of Hair</th>
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<th>Complexion</th>
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### Any Medications or Drugs Taken Regularly
- **Yes**
- **No** *(if "Yes" - Explain or list drugs)*

## FAMILY HISTORY

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## PHYSICAL CONDITIONS

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<th>Diabetes</th>
<th>Hypertension</th>
<th>Cardiopathy</th>
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<th>Hearing</th>
<th>Allergic Reactions</th>
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<th>Malignant Hypertension</th>
<th>Multiple Sclerosis</th>
<th>Cystic Fibrosis</th>
<th>Other</th>
<th>Mental/Functional Problems</th>
<th>Mental Retardation</th>
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## OTHER CHILDREN OF NATURAL PARENTS

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<th>Full Term or Premature</th>
<th>Age Begins to Talk (in weeks)</th>
<th>Age Begins to Walk (in weeks)</th>
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