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LEGAL ISSUES CONFRONTING FAMILIES AFFECTED BY HIV

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I. INTRODUCTION

The Diversity of Families Affected By HIV/AIDS

Families[1] affected by Human Immunodeficiency Virus ("HIV")

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The Council is the only organization in metropolitan Chicago devoted exclusively to providing a full spectrum of legal services and information to persons affected by Human Immunodeficiency Virus ("HIV"). Further information about the Council's important community-based work may be obtained by writing to Mr. Smith at the Council's office: 220 South State Street, Suite 2030, Chicago, Illinois 60604. The views expressed herein are those of the author and not necessarily those of the Council.

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1. For purposes of this article, "family" will include nontraditional families, such as gay families (also referred to as "domestic partners" or "significant others") and extended families. The type of legal advice given to a family may depend upon whether it is traditional or nontraditional. For example, legal spouses are responsible for each other's debts. This responsibility does not generally apply to domestic partners because they are not legally recognized as spouses.

The concept of the gay family has not been readily recognized in law, mainly because gays and lesbians have been denied the opportunity to marry. For law review articles discussing cases involving constitutional challenges by gays and lesbians seeking to marry, see generally Hafen, *The Constitutional Status of Marriage, Kinship, and Sexual Privacy: Balancing the Individual and Social Interests*, 81 MICH. L. REV. 463 (1983); Comment, *Constitutional Aspects of the Homosexual's Right To a Marriage License*, 12 J. FAM. L. 607 (1973); Comment, *Homosexuals' Right To Marry: A Constitutional Test and A Legislative Solution*, 128 U. PA. L. REV. 193 (1979); Note, *The Legality of Homosexual Marriage*, 82 YALE L.J. 573 (1973).

The definition of the nuclear family is being tested by domestic partnership ordinances, which at least attempt to confer some status or economic benefits upon unmarried cohabitants. Domestic partnership ordinances have been passed in numerous jurisdictions. According to the National Gay and Lesbian Task Force ("NGLTF") at least three counties (County of Alameda, CA; San Mateo County, CA; and Travis County, TX) and 11 municipalities (Seattle, WA; Berkeley, CA; Santa Cruz, CA; West Hollywood, CA; Los Angeles, CA; New

have numerous, often complex, legal concerns. Increasingly, HIV-infected women are poor, of color and uneducated.[2] These women have little support and lack knowledge of available services.[3] Some of these women turn to prostitution, and many have become HIV positive because they do not have the power to insist on condom usage.[4]

York, NY; Madison, WI; Takoma Park, MD; Ithaca, NY; Laguna Beach, CA; and San Francisco, CA) have domestic partnership ordinances which apply to local government employees and their families. *See* NGLTF, Current Recognition of Alternative, Non-Traditional and Diverse Families (available from Ivy Young, Families Project Director, NGLTF, 1734 Fourteenth Street, N.W., Washington, D.C. 20009-4309). Some corporations are beginning to extend domestic partnership benefits to employees. Barron, *Bronx Hospital Gives Gay Couples Spouse Benefits*, N.Y. Times, Mar. 27, 1991, at A1, col. 2. Montefiore Medical Center has become the largest private employer in the nation to provide the same health benefits for homosexual workers and their partners as for heterosexual employees and their spouses. *Id.* The hospital will require employees seeking to take advantage of this new policy to submit evidence, such as a driver's license, to show that an employee and his or her partner were living together, joint checking accounts to show "proof of financial interdependence" and sworn statements from the two people affirming that they were "each other's sole domestic partner." *Id.* at A1, col. 3.

Recently, the concept of the nuclear family has been successfully challenged in the courts. *See* Braschi v. Stahl Assoc., 74 N.Y.2d 201, 543 N.E.2d 49, 544 N.Y.S.2d 784 (1989). In *Braschi*, domestic partners lived in a rent controlled apartment, held joint bank accounts, shared safe deposit boxes and credit cards, and fulfilled financial obligations together. *Id.* at 213, 543 N.E.2d at 55, 544 N.Y.S.2d at 790. When one domestic partner died of AIDS, the other challenged a trial court decision permitting his eviction because he was not legally "family" or the "surviving spouse." *Id.* at 206-7, 543 N.E.2d at 51, 544 N.Y.S.2d at 786. The court of appeals noted that the protection against eviction "should not rest on fictitious legal distinctions or genetic history, but instead should find its foundation in the reality of family life." *Id.* at 211, 543 N.E.2d at 53; 544 N.Y.S.2d at 788-89. The court listed several factors which should be considered: exclusivity and longevity of the relationship; the level of emotional and financial commitment; how a couple has conducted their everyday lives and held themselves out to society; and the reliance placed upon one another for daily family services. *Id.* at 212-13, 543 N.E.2d at 55; 544 N.Y.S.2d at 790. However, the court noted that "[i]t is the totality of the relationship as evidenced by the dedication, caring and self-sacrifice of the parties which should, in the final analysis, control." *Id.*

2. *See generally* Gayle, Selik & Chu, *Surveillance for AIDS and HIV Infection Among Black and Hispanic Children and Women of Childbearing Age, 1981-1989*, 39 MORBIDITY & MORTALITY WEEKLY REP. 23 (1990); Gunan & Hardy, *Epidemiology of AIDS in Women in the United States, 1981 - 1986*, 257 J. A.M.A. 2039 (1987); Stuntzner-Gibson, *Women and HIV Disease: An Emerging Social Crisis*, 36 SOC. WORK 22 (1991); Wofsy, *HIV Infection in Women*, 257 J. A.M.A. 2074 (1987).

As this article went to press, the Centers for Disease Control ("CDC") reported a total of 16,330 cases of AIDS diagnosed in women, and projected that up to 80,000 women of child-bearing age may be infected with HIV *AIDS Virus Among Women*, N.Y. Times, Apr. 3, 1991, at A12, col. 5.

3. *See generally* Carr, Summary of Research Report: The Health Care and Social Service Needs of HIV-Positive Women and Children In Metropolitan Chicago, (February 1990) (available from the Visiting Nurse Association of Chicago or the AIDS Legal Council of Chicago).

4. *See* Gillespie, *Women and AIDS*, MS., Jan.-Feb. 1991, at 16 (women in prostitution with fragile economic situations "are less likely to refuse to have

Cultural Barriers To Accessing Health Care and HIV/AIDS Specific Services

There is a great stigma associated with HIV infection. Gay African-Americans and Hispanics face substantial homophobia[5] in their cultures.[6] Persons with HIV/AIDS are frequently ostracized

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sex with clients who won't wear condoms"). Battered women are also at a high risk of acquiring HIV because of their lack of self-esteem and inability to negotiate with their partners. Stuntzner-Gibson, *supra* note 2, at 23.

5. Homophobia is the fear and/or hatred of gay persons. *See* WEINBERG, SOCIETY AND THE HEALTHY HOMOSEXUAL 133 (1972)(revulsion towards homosexuals). *See also* J. BOSWELL, CHRISTIANITY, SOCIAL TOLERANCE AND HOMOSEXUALITY: GAY PEOPLE IN WESTERN EUROPE FROM THE BEGINNING OF THE CHRISTIAN ERA TO THE FOURTEENTH CENTURY 46 n.11 (1980)(author notes that although the word "homophobia" is often synonymous with anti-gay prejudice, it should mean "fear of what is similar," not "fear of homosexuality." The author suggests that the word "homosexophobia" might be more appropriate).

The Campaign To End Homophobia ("Campaign"), refers to four distinct but interrelated types of homophobia. (Unpublished materials available from the Campaign, P.O. Box 819, Cambridge, Massachusetts 02139, or from the AIDS Legal Council of Chicago). The four types of homophobia include:

Personal homophobia - This is prejudice. It is the personal belief that lesbian, gay, and bisexual people are sinful, immoral, sick, inferior to heterosexuals, or incomplete women and men. Prejudice against any group is learned behavior; people have to be taught to be prejudiced. Personal homophobia is sometimes experienced as the fear of being perceived as lesbian, gay or bisexual, out of the fear that one will be treated as if one were sinful, immoral, sick or inferior. This fear can lead to trying to "prove" one's heterosexuality.

Interpersonal homophobia - This is the fear, dislike, or hatred of people believed to be lesbian, gay, or bisexual. This hatred or dislike may be expressed by name-calling, verbal and physical harassment, and individual acts of discrimination.

Institutional homophobia (or *heterosexism*) - This refers to the many ways in which government, businesses, churches, and other institutions and organizations discriminate against people on the basis of sexual orientation. These organizations and institutions set policies, allocate resources, and maintain unwritten standards for the behavior of their members in discriminatory ways.

Cultural homophobia (or *heterosexism*) - This refers to social standards and norms which dictate that being heterosexual is better or more moral than being lesbian or gay, and that everyone is heterosexual or should be. While these standards are not written down as such, they are illustrated each day in television shows and print advertisements where virtually every character is heterosexual and every sexual relationship involves a female and a male; or in the assumption made by most adults in social situations that all "normal" children will eventually be attracted to and marry a person of the other sex.

6. This stigma is particularly acute for gay African-Americans and Hispanics. *See generally* Sullivan, *Gay Life, Gay Death: The Siege of a Subculture*, THE NEW REPUBLIC, Dec. 17, 1990, at 19 (many black and Hispanic men would sooner admit to being a junkie than to being gay). For a further discussion of homophobia in the African-American community, *see* Smith, *HIV/AIDS And Workplace Discrimination: Dickens Revisited — "It Was The Best Of Times, It Was The Worst Of Times"*, 22 U. WEST L.A. L. REV. 19 (1991).

by their families.[7] They may not seek appropriate health care/medical services for a variety of reasons, some of which are cultural. For example, in the Hispanic community cuanderos,[8] spiritists[9] and homeopaths[10] are often the primary health care providers. In the Afrocuban community, santeria[11] is a belief system which has critical implications as to whether Afrocubans are streamlined into traditional health care systems. In sum, those infected with HIV who are not mainstreamed into the traditional health care delivery system, and instead rely on these folk remedies, are denied the opportunity to take advantage of numerous

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7. Latinos, for example, are often stripped of family support when they become infected, and are thrust into a devastating cycle of rejection, isolation and homelessness. Stuntzner-Gibson, *supra* note 2, at 25.

8. Cuanderos are Mexican folk healers. *See generally* DOWLING & LOPEZ, *Traditional Medicine Among Mexican-Americans*, URBAN FAMILY MEDICINE 222 (R. Birrer ed. 1987); GIACHELLO, *Hispanics and Health Care*, HISPANICS IN THE U.S.. THE NEW SOCIAL AGENDA 159 (1985); Lopez, *Cuanderismo: A Healing Art*, 5 INTERCAMBIOS 26 (1990); Mull & Mull, *Cross-Cultural Medicine: A Visit With a Cuandero*, 139 WEST. J. MED. 730 (1983). Practitioners of cuanderismo originated in pre-Columbian times and were influenced by 16th century Spanish health care traditions. The cuanderos use herbs, ritual prayer, music, dance and massage to cure people.

Unfortunately, some folk healers may sell "fraudulent" remedies. *See* Segal, *Defrauding The Desperate: Quackery And AIDS*, 21 FDA CONSUMER 17-19 (1987)(author notes that an herbalist from Honduras who brought his "bag of miracles" to Brooklyn markets his cure for AIDS starting at $500; however, this healer prescribes the same regimen of diet and herbs for all ailments).

The fact that some healers may be fraudulent, however, is not to disparage the efficacy of alternative therapies. For example, there is some anecdotal evidence that acupuncture may successfully treat diarrhea that is resistant to all standard drugs.

9. Spiritism can be viewed as a health care system or folk psychotherapy. *See* Berthold, *Spiritism as a Form of Psychotherapy: Implications for Social Work Practice*, 70 SOC. CASE WORK 502 (1989). Studies indicate that about one third of adult Puerto Ricans go to a medium for help at some point in their lives. *Id.* at 502.

Spiritists are utilized for many different reasons. For example, in the Puerto Rican culture, a severe stigma is often attached to visiting a psychiatrist. Consequently, many Puerto Ricans go to a spiritist as a normal and acceptable means of coping with stress. *Id.* at 504.

10. Homeopathy is a "system of medical practice founded by Hahnemann of Leipsic about 1796 according to which diseases are treated by the administration (usually in very small doses) of drugs which would produce in a healthy person symptoms closely resembling those of the disease treated." OXFORD ENGLISH DICTIONARY 338 (2d ed. 1989). For a further discussion of homeopathy, *see generally* Ullman, *The Revival of Homeopathy*, UTNE READER 88 (Jan.-Feb. 1988).

11. Among Santeria believers, disease is considered to be a result of both natural and supernatural causes. *See* Sandoval, *Santeria: Afrocuban Concepts of Disease And Its Treatment In Miami*, 8 J. OPERATIONAL PSYCHIATRY 52 (1977). Santeros also believe in the ever-present properties and power of plants, herbs, and weeds. *Id.* at 59. The plants are considered very powerful, and the prescription of potions obtained from them is seen as an important part of the treatment of diseases. *Id.*

services available to them.[12]

In situations where spouses or significant others are living together and both are HIV positive, one individual is often blamed for causing the other's infection. Upon the death of an HIV positive parent (or significant other), this reason is often used to deny custody or visitation to the living, but sick, parent. This blaming is prevalent in situations where an individual has become HIV positive through unpopular behaviors, such as through the use of intravenous ("IV") drugs[13] or sexual activity (including homosexual or bisexual activity) outside the bounds of marriage or the primary relationship.

Chicago Demographic Profile of Minority Women Affected by HIV

In 1990, Andrea Carr,[14] reported on the demographics and profile of HIV positive women in Chicago. Of 227 HIV-positive women in the study, 43.5% were Black, 21.2% were Hispanic, 31.1% White, and 4.2% Other. These women had 592 children.[15] Sixty-eight percent of the women were on public aid — for most, this was their only form of income. Only 19% of the women surveyed had private health insurance, 10% had no form of health insurance, and the remainder relied upon Medicaid to cover medical costs. Twenty-two percent of the women in Carr's study had no friend or relative who was willing to help them cope with their disease; another 32% had only one such person.[16] Many of these women lacked a support system, informal or otherwise: 34.7% had no informal support, such as friends to help with child care, while 54% had no formal support, including treatment and counseling.

HIV positive women with children often neglect to focus on their own personal needs, such as health care and support systems, but instead concentrated on the needs of their children.[17] In part,

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12. Medical social workers and case managers in hospitals can be of great assistance in accessing a wide variety of services for patients with HIV/AIDS. For example, medical social workers knowledgeable about community resources can access programs such as "Meals on Wheels," in-home services that can shop and clean for clients, counseling, support and other psychosocial services, legal services, housing and financial assistance.

13. Drug users and gays and lesbians are outside of society's empathy. *See* Kagay, *Survey Finds Antipathy Toward Victims of AIDS*, N.Y. Times, Oct. 14, 1988, at 8, col. 4.

14. *See* Carr, *supra* note 3, at 1-3.

15. Carr, *supra* note 3, at 7-8. Recent studies project that nationally 1,500 to 2,100 babies could be born with HIV in the United States each year. *AIDS Virus Among Women*, N.Y. Times, Apr. 3, 1991, at A12, col. 5.

16. Carr, *supra* note 3, at 17.

17. *See* Testimony of Dr. Elizabeth Gath to the National Commission on AIDS, March 13, 1991. (copy of this testimony is available from the Council). Dr. Gath, Associate Director of the Women and Children with AIDS Project at

due to their failure to focus on their own health care needs, the survival rates for these women, after being diagnosed with AIDS, is much lower than the survival rates for men.[18]

When a family affected by HIV/AIDS initially contacts a lawyer, the lawyer must appreciate the degree of stress upon the family and must initially be aware of the possibility of a conflict of interest.[19] The person initially seeking legal consultation, whether the spouse, sister, brother or other member of the domestic partnership/extended family, will be desperate for fast answers to many complex questions. This individual may be seeking unequivocal assurances which the lawyer will not be in a position to give, largely because the legal answer often depends upon contingencies which are uncertain at the time the client seeks legal advice.

Such desperation occurs because of a fear of losing the shared home and the possible indigency the family may face because the sick wage earner may lose her job and become unable to meet current financial obligations. When receiving such calls, the lawyer can assist the client by focusing on the problem from a more realistic perspective, particularly since the lawyer has some distance from the problem and can prioritize the issues presented. For example, the client who is fearful of losing her job, her home and her ability to maintain private education for her children, must be counseled to focus upon discrete current problems which can be handled (e.g. applying for disability insurance or long-term disability). By persuading the client to focus on current problems, and then ultimately to complete the tasks necessary to resolve these problems one at a time, the attorney will give the client a sense of accomplishment and a feeling that the future is not so uncertain.

Cook County Hospital, Chicago, Illinois, testified that among the many things she has learned from HIV infected/affected families include: parents want the best for their children; in seeking the best for their children, parents struggle for many, basic needs; and, parents will seek care for their child before seeking services for themselves.

18. *See* Brownworth, *Increased Risks For Women With AIDS*, CHICAGO OUTLINES, Nov. 26, 1987, at 1, col. 1. Brownworth reports of a study conducted by Dr. Fischl at the University of Miami who found that survival rates among women after diagnosis were less than half of those of men. Of the 119 women studied, the average life expectancy for women was 6.6 months and for men was 14 months. *See also* Kolata, *Women with AIDS Seen Dying Faster; Data Show Sharp Difference in Comparison with Men*, N.Y. Times, Oct. 19, 1987, at A10, col. 6 (Dr. Paul Harder of San Francisco examined the life expectancies of 7,074 people with AIDS who had been diagnosed before 1987, and found that women in the study lived an average of only 40 days after diagnosis, while men lived an average of 16 months or more).

19. Lawyers must appreciate the fact that spouses or domestic partners may develop interests adverse to each other where either one or both spouses/domestic partners is HIV positive. *See generally* MODEL CODE OF PROFESSIONAL RESPONSIBILITY DR 5-105 (1990).

II. LEGAL ISSUES CONFRONTING FAMILIES AFFECTED BY HIV

The legal literature discusses few legal concerns of families affected by HIV.[20] The main purpose of this article is to highlight the variety of legal issues that will confront families affected by HIV/AIDS. As a consequence of understanding these issues, practitioners will more effectively be able to meet the concerns of their clients.

The types of legal issues confronting families affected by HIV/AIDS will vary considerably with the income level of the family (and often with the traditional or nontraditional nature of the family). At the Council, low income families have been mainly concerned about guardianship of their children. Families with more substantial incomes, while concerned with issues of guardianship, have also focused on issues of income preservation, such as filing for bankruptcy to protect the marital home, or filing for divorce to avoid responsibility for the debts of the HIV positive spouse.

A. Guardianship Issues

Establishing Guardianship by Will

The legal need most frequently reported as "imminent" by indigent HIV positive women of color is guardianship of their children. Traditionally, the most simple legal means by which to "establish" guardianship is through a guardianship provision in a will.[21] Via this mechanism, a parent names a trusted individual, and preferably alternate individuals, to care for their children upon the parent's death. If the testator is not married to the father of the child, or the parent or parents are IV drug users and the child in question is a ward of an appropriate state child-care agency,[22] a

20. For a discussion of the legal issues of HIV positive women, see generally Zarembka & Franke, *Women In The AIDS Epidemic: A Portrait of Unmet Needs*, 9 ST. LOUIS U. PUB. L. REV. 519-541 (1990); Zarembka & Franke, *Women & AIDS: Epidemic of Societal Denial, Blame & Poverty*, THE EXCHANGE, Feb. 1991, at 1, col. 1 (The Exchange is the monthly newsletter of the National Lawyers Guild AIDS Network).

21. Although a guardianship provision in a will does not formally establish guardianship, assuming a parent has selected an appropriate individual (e.g., one who will act in the best interests of the child and who is financially capable of taking care of the child) to act as guardian, this individual can readily obtain guardianship after the death of the parent. LaGamma & Herb, *Providing For the Future Care of Children*, in AIDS PRACTICE MANUAL: A LEGAL AND EDUCATIONAL GUIDE §§ 5-10-5-12 (1991) (available from National Lawyers Guild AIDS Network, 558 Capp Street, San Francisco, CA 94110). LaGamma and Herb also provide an excellent discussion of ethical concerns for attorneys, and focus on the tension between the obligations to represent the choices of the client/parent and the attorney's perception that those choices may not be in the best interest of the child.

22. In Illinois, the state child welfare agency is the Department of Children and Family Services ("DCFS").

guardianship provision in a will cannot usurp either the authority of another parent or of the state.

Consider the situation in which the mother of a child wishes to name a guardian other than the biological father. The mother cannot unilaterally terminate the father's parental rights via a guardianship provision in a will.[23] As a practical mattter, however, there is a real possibility that the father has already died from HIV/AIDS or is also HIV positive if he shared IV drugs with the mother.[24] Consequently, the father may not be in a position to obtain custody of the child in question should the mother seek to terminate his parental rights. If the father has died, the mother could execute a guardianship provision in a will naming a friend/relative as guardian upon the mother's death.

Many individuals with a current or past history of IV drug use have one or more children in foster care.[25] A guardianship provision in a will, as already mentioned, cannot preempt the state's authority in deciding the child's appropriate placement once the child has become a ward of the state. Many HIV positive clients often object to the continued placement of their children in foster care.[26]

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23. The Supreme Court has held that because the parental right is "fundamental", a higher burden of proof must be met to terminate it. *See generally* Santosky v. Kramer, 455 U.S. 745 (1982)(the fundamental liberty interest of natural parents in the care, custody, and maintenance of their child is protected by the fourteenth amendment and thus cannot be terminated by the state without adequate due process, even upon a finding that the child is "permanently neglected."); Stanley v. Illinois, 405 U.S. 645 (1972)(unmarried fathers have a cognizable and substantial interest in the care and custody of their children born out of wedlock; however, an unmarried father's "interests are readily distinguishable from those of a separated or divorced father" in that "even a father whose marriage has broken apart will have borne full responsibility for the rearing of his children during the period of the marriage.").

For law review articles discussing constitutionally mandated standards for termination of parental rights, see generally McCarthy, *The Confused Constitutional Status and Meaning of Parental Rights*, 22 GA. L. REV. 975 (1988). As a general rule, the party seeking to terminate the parent's custodial right must show: (1) parental unfitness, and (2) that the unfitness is detrimental to the best interests of the child. The standard of proof is by clear and convincing evidence. *Santosky*, 455 U.S. at 769.

24. This reality has been concurrently observed by attorneys serving HIV positive women in New York. *See generally* LaGamma & Herb, *supra* note 21, at § 5 (1991).

25. If an HIV positive parent has several children in foster care (because the parent has formerly been an active IV drug user), it may take years to resolve visitation disputes between the parent, the foster caretaker and the state agency responsible for regulating the conditions of foster care. In Illinois, the Council is trying to work with the courts, the DCFS and mediators to mediate such emotional disputes. As advocates for HIV positive parents, the Council seeks to widen the ability for sick parents to bond with their children. The courts are not particularly well-equipped, however, to resolve emotion-laden disputes.

26. Parents might also object to the nature of the child's placement. For example, HIV positive parents may feel that the state has selected unsuitable

For example, the parent with HIV/AIDS who was once an IV drug user often contests the continued placement of his/her child in foster care. HIV positive symptomatic individuals who are no longer drug users[27] often wish to get back their children and/or increase their visitation/custody arrangements. Since a large number of former drug users have children in foster care placement,[28] the volume of legal need generated by HIV positive drug users seeking greater access to their children will be staggering.[29]

Consequences of Establishing Guardianship During the Parent's Life

There are obvious practical difficulties in establishing guardianship during the parent's life. The primary diffculty is the act of relinquishing "parental control" over the child.[30] As a result, vari-

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foster care parents. In Illinois, DCFS has been sued for historically placing wards with families who are not relatives of the parents.

27. In Illinois, DCFS will periodically monitor the urine of the parent who was formerly a drug user. Before DCFS will consider expanded custody/visitation for this parent, the parent will generally need to show not only that his or her drug use is controlled, but also that the parent has the ability (e.g., can live independently in the community) and the resources (e.g., has sufficient job-related income) to properly care for the child. The Council had one model client who, due to stress, had a relapse and began using drugs. Unfortunately, state child care agencies, such as DCFS, and the courts do not look favorably on such relapses and, consequently, tend to deny any increased visitation sought by the parent with HIV/AIDS.

In *Norman v. Suter*, No. 89 C 1624 (N.D. Ill. 1990) (consent order) attorneys from the Legal Assistance Foundation of Chicago sought declaratory and injunctive relief against policies and practices of DCFS under which plaintiffs alleged they had lost, were at risk of losing, or would in the future lose custody of their children to DCFS because of their inability to provide "adequate" food, shelter, clothing, or housing for the children. The settlement provides, in part, that DCFS shall not remove any child from a parent because of the living circumstances or lack of subsistence, unless there is a reason to believe that conditions in the home present an imminent danger to the child's life or health. *Id.* at 7-8. In addition, DCFS will not separate children from their parents simply because the family is residing in a shelter. *Id.* at 8-9. DCFS will set aside about $1.8 million annually for cash assistance to families in danger of losing custody because of inadequate food, shelter or clothing for their children. Under the cash assistance program, families can pay initial rent and security deposits. Not later than October 1, 1991 DCFS shall establish a program to assist clients in locating adequate housing. *Id.*

28. For a discussion of the overburdened foster care system, *see infra* note 47.

29. The bulk of the legal needs generated by HIV positive drug users seeking increased visitation will fall upon public defenders (juvenile division) who will represent these individuals.

30. *See* LaGamma & Herb, *supra* note 21 at § 5-2 ("Although in some states a parent can maintain physical custody and control over important aspects of a child's life after a guardianship has been established, in other states a guardian assumes control over all aspects of the child's life").

ous informal arrangements are often worked out.[31]

B. Marital Issues

Child Custody and Visitation Issues For Traditional Families

There have only been a handful of cases in which an HIV positive parent has been denied custody and/or visitation rights.[32] Some judges have had hysterical reactions to persons with HIV/AIDS. Thus, HIV positive parents who are also gay could face additional, perhaps substantial, prejudice in the court system.[33] Unfortunately, this prejudice is due to the myth that the gay parent[34] will not be an appropriate role model[35] or will, among other things, attempt to persuade the child to become gay (e.g., the "pied

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31. *Id.* at § 5-4. LaGamma and Herb state that "[w]ith some clients, formal arrangements are just not feasible. The parent may be fearful of losing her child or of alienating other family members. She may not have told her family of her HIV status. She may procrastinate in producing papers or fail to keep appointments. . . ." *Id.*

32. *See generally Stewart v. Stewart*, 14 FAM. L. REP. 1315 (Ind. Ct. App. 1988)(Indiana Appeals Court overturned a trial court's decision, which had terminated visitation rights for a father who tested positive for HIV antibodies, as an "abuse of discretion" because of its failure to place the appropriate evidentiary burden on the mother to show danger to the child); Wallace v. Wallace, No. VFL 013212 (Cal. Super. Ct. 1988), reported in AIDS POL'Y & L., Nov. 2, 1988, at 2, col. 1; "Jane" W. v. "John" W., 127 Misc. 2d 24, 519 N.Y.S.2d 603 (N.Y. Sup. Ct. 1987).

For law review articles discussing this topic, *see generally* Comment, *The Effects of AIDS On Child Custody Determinations*, 23 GONZ. L. REV. 167 (1987-88); Note, *Public Hysteria, Private Conflict: Child Custody And Visitation Disputes Involving An HIV Infected Parent*, 63 N.Y.U. L. REV. 1092 (1988).

33. *See generally* Comment, *Out of the Closet And Into The Courts: Homosexual Fathers And Child Custody*, 93 DICK. L. REV. 401 (1989) [hereinafter *Homosexual Fathers*].

34. About 25% of self-identified gay men father children. *See generally* Miller, *Gay Men and Their Children*, 21 FAM. COORDINATOR 544 (1979). Gay men, however, have historically less frequently fought for child custody and visitation rights than lesbian women. *See generally* Rivera, *Our Straight Laced Judges: The Legal Position of Homosexual Persons in the United States*, 30 HASTINGS L.J. 799 (1979). This has perhaps been due to the fact that men who openly assert their "sexual orientation" in a custody battle traditionally had more (at least economically) to lose than women. In other words, lesbians traditionally have not had the earning power of gay men, and, therefore, would not lose high paying jobs if their sexual orientation were known. These differences in earning power are very slowly becoming more equalized.

35. For law review articles discussing court cases denying custody and visitation to gay and lesbian parents based on common stereotypes of gay persons, see generally Comment, *Burdens On Gay Litigants and Bias In The Court System: Homosexual Panic, Child Custody, and Anonymous Parties*, 19 HARV. C.R.-C.L. L. REV. 497 (1984). Courts consider gay parents to be improper role models, in part because they consider homosexual relations immoral. *See* Constant A. v. Paul C.A., 344 Pa. Super. 49, 496 A.2d 1 (Pa. Super. Ct. 1985)(where the trial court found that "the natural mother's lesbian relationship shows her moral deficiency." *Id.* at 50, 496 A.2d at 3. Although the appellate court did not necessarily agree with the trial court's finding regarding "morality," the appellate court acknowledged that "there is considerable opinion, belief and law in

piper" theory).[36] Courts have also based gay and lesbian custody/visitation decisions on the fact that the children would face future (if not present) social harassment.[37]

Since HIV/AIDS is not transmitted via casual contact,[38] sick parents should be allowed generous custody or visitation arrangements with their children. Children should certainly have the opportunity to know a parent before the parent dies. Although courts have recognized this critical "psychological" factor, a parent's physical health is generally a factor courts still evaluate when determining the best interests of the child.[39]

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this country, which cannot be ignored, and which supports such a conclusion." *Id.* at 53, 496 A.2d at 5.

Numerous courts have conditioned a child's visitation with the gay parent upon the absence of the parent's lover or significant other. *See* Irish v. Irish, 7 FAM. L. REP. 2256 (Michigan Court of Appeals held that a lesbian could not have contact overnight with her lesbian partners while the children visited); Woodruff v. Woodruff, 6 FAM. L. REP. 2250 (North Carolina Court of Appeals allowed the father visitation but specified that his child could not be in the presence of the father's male lovers, nor was he to have any friends visit him at home when the child was there). These conditions imposed by courts are presumably due to the belief that gay parents are not proper role models because of their illicit lifestyle.

36. *See generally* KIRK & MADSEN, AFTER THE BALL: HOW AMERICA WILL CONQUER ITS FEAR AND HATRED OF GAYS IN THE 90'S 42 (1989)(authors note a 1970 survey conducted nationwide by the Institute of Sex Research which found that 43% of the public believed that all or most young homosexuals became that way because of recruitment by older homosexuals). Most gay men, however, are less likely than heterosexuals to be child molesters. *See* MOHR, GAYS/JUSTICE: A STUDY OF ETHICS, SOCIETY & LAW 24-25 (1988)(most widespread and persistent abusers are a child's father, stepfather or mother's boyfriend).

37. For a further discussion of the social harassment directed at children in gay and lesbian custody/visitation disputes, see generally, *Homosexual Fathers*, *supra* note 33, at 416-17 (author finds three areas of weakness in judiciary's denial of custody based upon social harassment: the possibility that there could be social harassment should not be accepted *per se* without a thorough investigation; court should determine, if there is harassment, if it is avoidable by denying gay or lesbian parent custody/visitation rights; judges must not give effect to their private biases (e.g., denying child custody/visitation on the fear of the child's social harassment is effectively legalizing private societal biases).

38. The "fear of contagion" was recently exacerbated by the CDC's reports of transmission of HIV to patients by HIV positive dentists. *See Epidemiologic Notes and Reports: Update, Transmission of HIV Infection During An Invasive Dental Procedure - Florida*, 40 MORBIDITY & MORTALITY WEEKLY REP. 21 (Jan. 18, 1991). Such information will undoubtedly cause some judges to be increasingly concerned about an HIV positive parent's contact with his/her child and the risks of transmission. *See generally* Altman, *U.S. Experts Try To Estimate AIDS Infections By Doctors*, N.Y. Times, Feb. 7, 1991, at A10, col. 5 (CDC estimates that as many as 128 or as few as 13 patients may have been infected with HIV by their dentists or surgeons).

39. *See In re* Marriage of Carney, 24 Cal.3d 725, 598 P.2d 36 (1979) where the California Supreme Court held that public policy weighed against denying custody solely on the basis of the parent's disability. The *Carney* court refutes the importance of a parent's ability to play sports, drive the child places, and otherwise have a "normal" relationship with the child. The court remarks that "[h]owever limited his bodily strength may be, a handicapped person is a whole

Child Custody and Visitation Issues for NonTraditional Families

A parent's ability to assert any custody interest over his or her children may be more difficult if the parents were never married.[40] For example, the "rights of parentage" are often necessary to assert parental authority in the schoolplace, access to health care and access to government benefits (e.g., AFDC benefits).[41] Thus in a situation where the biological parents of a child were never married and one of the parents has just died of HIV/AIDS, the other parent should consider establishing parentage.

Other Visitation Issues Concerning NonTraditional Families

Significant others/domestic partners have had problems visiting their lovers in hospitals. For example, in the renowned case of *Guardianship of Karen Kowalski, Ward*,[42] for years a lesbian partner was denied the opportunity to visit her lover, who had become disabled with a spinal cord injury, because the injured woman's family refused to admit that their daughter was a lesbian.[43] In reaction to situations similar to those presented in *Kowalski*, some states have amended their Power of Attorney Act to allow non-family members, named as agents in powers of attorney documents, the same authority as family members to visit the principal in the

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person to the child who needs his affection, sympathy, and wisdom to deal with the problems of growing up." *Carney, supra*, 24 Cal. 3d at 739, 598 P.2d at 44. For a discussion of *Carney, see* Comment, *The Effect of AIDS on Child Custody Determinations*, 23 GONZ. L. REV. 16, 176-77 (1987-88); *In re* Marriage of Ford, 84 Ill. App. 3d 810, 415 N.E.2d 546 (1980)(court held evidence that a parent was unable to play certain sports with his children, due to physical injury, was a relevant factor to be considered in awarding custody).

40. The author's discussion of this situation does not wish to impute any stigma to children of parents born out of wedlock. For certain legal reasons, however, such situations will be considered nontraditional. See *supra* note 23 on termination of parental rights.

41. *See* 42 U.S.C. § 606(a)(1) (West 1983)(under AFDC program, eligible caretaker relatives include mothers, fathers, sisters, brothers, grandparents, great-grandparents, aunts, uncles, great or great-great aunts and uncles of whole blood, step-father, step-mother, step-sister or brother or spouses of any of the above named).

42. 392 N.W.2d 310 (Minn. Ct. App. 1986).

43. The *Kowalski* case has received extensive coverage with the gay and lesbian press. Klose, *The Fight To Free Sharon Kowalski Continues*, Windy City Times, Aug. 4, 1988, at 16, col. 1. This case has also received attention in the mainstream press. *See generally* Brozan, *Gay Groups Are Rallied to Aid 2 Women's Fight*, N.Y. Times, Aug. 7, 1988, at 13, col. 1 (Ms. Thompson urged gay couples to draw up powers of attorney, wills and other protective legal documents or they have "no legal right to 'spousal' property or decision-making."); Brozan, *Visit Marks Struggle on Gay Rights*, N.Y. Times, Feb. 8, 1989, at 11, col. 1. In the most recent development in the case, Ms. Kowalski's father resigned as guardian, citing two heart attacks and the strain of repeated court challenges as his reasons for doing so, and the judge appointed a third party to act as guardian. *See generally* Brozan, *2 Sides Are Bypassed in Lesbian Case*, N.Y. Times, Apr. 26, 1991, at A13, col. 1.

hospital.[44]

Distribution of Property Upon Divorce

When one party to a divorce is sick and the other is healthy, there remains a critical policy question that must be addressed: should the financial needs of the sick spouse outweigh the financial needs of the healthy spouse and the remainder of the family? In other words, should the court impoverish the sick spouse at the expense of preserving the family's assets?[45]

C. *Children's Issues Including Child Care and Placement for the Growing Number of HIV Positive Children*

To the extent that HIV positive women have small support networks and large families, the already serious problem of neglected children and border babies[46] will mushroom. The HIV/AIDS crisis will further strain the resources of the presently overburdened foster care system.[47]

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44. *See generally* ILL. REV. STAT. ch. 110 1/2, para. 804-10 (West Supp. 1990)(the Illinois statute further provides that the "agent" may have the authority for hospital visitation notwithstanding hospital policy to the contrary). For a general discussion of the rights of nonfamily members to make proxy decisions, see Note, *Broadening Anachronistic Notions of "Family" in Proxy Decisionmaking for Unmarried Adults*, 41 HASTINGS L.J. 1029 (1990). An author notes that "[n]o state explicitly includes close friends or lovers as appropriate surrogate decisionmakers, or suggests that they may be people who, because of their intimate relationships with the incompetent adult and their knowledge of the patient's preference regarding treatment, should be consulted about treatment procedures." *Id.* at 1039. The author also analyzes guardianship statutes and notes that only Alaska and Montana provide that: "a relative or friend who has demonstrated a sincere, longstanding interest in the welfare of the incapacitated person may be added to the list of potential guardians." *Id.* at 1047 (citing ALASKA STAT. § 13.26.145(d)(5) (1985); MONT. CODE ANN. § 72-5-312(2)(f) (1989)).

45. This situation has many other analogies in the law, e.g., Alzheimer's disease.

46. Border babies are newborns whose medical condition does not require inpatient care at a hospital, but who are unable to return home or be cared for by the child welfare agency for a variety of reasons, including their HIV status. ABA AIDS COORDINATING COMM., AIDS: THE LEGAL ISSUES 212 (1988)(discussion draft). According to the ABA AIDS Coordinating Committee, most agencies have not yet developed sufficient or adequate alternative placement facilities for border babies.

The already serious problem of border babies defies the mandates of the Federal Adoption Assistance and Child Welfare Act, *infra* note 51, that every child needing out-of-home care be placed in the least restrictive setting.

47. For a general discussion of the overburdened foster care system, *see* Barden, *Foster Care System Reeling, Despite Law Meant To Help*, N.Y. Times, Sept. 21, 1990, at A1, col. 5 (trends as of the date of the article indicate that the number of foster parents is falling, with fewer foster parents caring for more children (average of three children/family)).

Most of the children in the foster care system entered the system because of their parents' drug usage or alcoholism. *Id.* at A10, col. 4. According to the

Children with HIV/AIDS will need legal representation during the course of their illness.[48] Perhaps their most urgent need will be that of obtaining social security disability benefits.[49] Children with disabilities are eligible for numerous other services but frequently cannot broker such services because not enough child advocates exist to assist in obtaining these services.[50] Also upsetting is the harsh fact that larger families, where one or both parents are deceased due to HIV disease, will need to split up amongst several individuals

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presiding judge of the Juvenile Courts in Los Angeles, about 90 percent of the 20,000 children who will come before his courts this year are there because of parental drug or alcohol abuse. *Id.* And according to the article, a recent survey in New York State found that parental drug or alcohol abuse was involved in more than 60 percent of foster placements. *Id.* In 1989, according to one New York city official, 3,000 children entered foster care from hospitals presumably because their mothers were addicted to drugs at the time their children were born. *Id.*

48. Children who are not HIV positive, but born to HIV positive parents, will also need legal representation at some point during the course of the parents' HIV disease. However, the legal needs of this group will not be discussed herein.

49. Disabled children have previously had difficulty obtaining social security disability benefits. *See* Sullivan v. Zebley, 493 U.S. 521 (1990)(Supreme Court found unconstitutional the means via which the Department of Health and Human Services ("DHHS") adjudicated "disability" for children, because the standards by which children's disability benefits were adjudicated were more stringent than standards used to evaluate claims of disabled adults). For example, agencies considering disability claims for adults would often consider medical evidence of the disability as well as the adult's ability to engage in certain work-related activities ("residual functional assessment"), *e.g.*, ability to stand, walk, lift, push, pull, bend, reach and carry. *See* 20 C.F.R. § 404.1520a (1990). Children's claims for disability benefits, however, were only evaluated based on medical evidence. *Sullivan*, 493 U.S. at 890. The DHHS did not formerly assess age appropriate activities.

In response to the Supreme Court's *Sullivan* decision, DHHS has published final regulations, which will be open for public comment. *See generally* 56 Fed. Reg. 5534 (1991)(to be codified at 20 C.F.R. pt 416)(proposed Feb. 11, 1991). These regulations propose a new analysis for the disability claims of children. According to the regulations, the Social Security Administration ("SSA") will sequentially evaluate the following four questions: 1) whether the child is engaged in substantial gainful activity (e.g., if a child is working, he/she will not be considered disabled); 2) whether the child's impairment or combination of impairments is severe; 3) whether the child has a medically determinable impairment that meets or equals in severity a listing and, if not, whether the functional consequences of the child's impairment or combination of impairments functionally equal a listing; and 4) whether the child's severe impairment so limits the child's ability to function in an age-appropriate manner that the limitations are comparable in severity to those that would disable an adult. *Id.* at 5535. The new standards recognize that children under 6 months of age are difficult to evaluate because they do not have clear medical or functional findings. *Id.* at 5537. Consequently, the SSA will determine whether such children have a substantially reduced ability to grow, develop or mature in an age-appropriate manner. *Id.*

50. A discussion of the numerous services that disabled (and often indigent) children are entitled to is beyond the scope of this article. An important resource to consult is JAMESON, *Health Care for Low Income Children*, REPRESENTING THE CHILD CLIENT (MB) (1987).

because one individual will be unable to economically support numerous children.

Adoption vs. Placement in Foster Care

Individuals who might adopt a healthy child may be deterred from adopting an HIV positive child for economic reasons. Since parents adopting children with HIV/AIDS might be eligible for federal financial assistance, such parents must know the child's HIV status.[51] Incentives need to be provided that encourage foster care placement (or adoption) of children with HIV/AIDS. Such incentives are particularly needed in light of the growing problem of border babies[52] in foster-care, until it is learned that the babies are healthy and, consequently, more economically suitable for adoption.

Legal Standards Regulating Placement of Children In Foster Care

Children within the care of state child welfare agencies are traditionally placed in foster family homes that are subject to licensure by either the state or county. Although licensure requirements vary from state to state, the California Department of Social Services has taken the position that the placement of children with special medical needs in foster family homes is prohibited under state law.[53] A few courts have addressed similar issues, such as the liability for the negligent placement of children with infectious diseases.[54] Since some of the opportunistic infections of HIV/AIDS

51. The Federal Adoption Assistance and Child Welfare Act, 42 U.S.C. §§ 602-628 (1988), provides subsidies initially created to give families financial and medical assistance so that children who might be difficult to place, including those with serious medical conditions, might be adopted. Any subsidy agreement, however, must be entered into before finalization (although the state's financed program could cover post adoption agreements).

52. *See supra* note 46 for a definition of "border babies."

53. The California Department of Social Services ("Department") apparently bases its opinion on a California statute which authorizes the provision of "incidental" medical services that do not constitute a "substantial component" of the services provided by a foster family home. State officials argue that children with HIV/AIDS require more than "incidental" medical care, and, therefore, cannot be legally placed in foster family homes. The State's position, however, has been subject to legal challenge. *See* United Cerebral Palsy Assoc. of Ca. v. McMahon, No. C-549956 (Superior Court of San Diego, complaint filed September 30, 1985)(according to a conversation with a member of the United Cerebral Palsy Association, the aforementioned lawsuit was dropped after the client's death).

54. *See* Vaugh v. North Carolina Dep't of Human Resources, 296 N.C. 682, 252 S.E.2d 792 (1979) where the state agency was held liable for placing a child with an infectious disease, cytomegalovirus, known to cause birth defects, with a mother who was pregnant. The agency was aware of the condition of both the child and foster mother, who had an abortion as a result of contracting the infectious disease.

are also infectious, such as tuberculosis,[55] child placement agencies should disclose a child's HIV status to foster care parents. Compelling medical reasons indicate the appropriateness of disclosing a child's HIV status. For example, children with HIV/AIDS who are in school and might receive vaccinations should not receive certain polio vaccines because the polio virus, shed in the stool, might be spread to the entire family.[56]

D. Economic Issues in Families Affected by HIV

HIV/AIDS can be financially devastating.[57] As with all other debilitating diseases, persons with HIV/AIDS eventually are unable to work. With loss of employment and its associated income stream, many individuals lose their group health and life insurance benefits.[58] Even for individuals fortunate enough to have disability insurance (which, most of the time, only pays 50-60% of lost income), the significant decrease in "disposable" or "discretionary" income is traumatic. For those without disability insurance who must depend exclusively on public aid, and/or social security disability benefits or supplemental security income, the significant de-

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55. Tuberculosis ("TB") is the fifth most common opportunistic infection that persons with AIDS may have. *See Increase in Tuberculosis Tied To Spread of AIDS*, N.Y. Times, Jan. 3, 1988, at 12, col. 4 (in Florida, statistics indicate that 10 percent of the state's first 1,094 reported AIDS patients also had TB; according to the CDC, AIDS infections of patients with dormant TB infections "seem to allow the progression to actual illness."); Roberts, *Tuberculosis On Rise In Chicago Area: Experts Attribute Increase To AIDS*, Skyline, Jan. 24, 1991, at § 2, at 7, col. 1 (in 1990, 61% of the cases of TB reported in the state of Illinois were in Chicago; consequently, about 23 persons/100,000 have TB in Chicago, compared with the national average of 9 persons/100,000).

56. Davis, Bodian, Price, Butler & Vickers, *Chronic Progressive Poliomyelitis Secondary to Vaccination Of An Immunodeficient Child*, 297 NEW ENG. J. MED. 241 (1977); Nkowane, Wassilak, Ovenstein, Bart, Schonberger, Hinman & Kew, *Vaccine Associated Paralytic Poliomyelitis: United States: 1973-1984*, 257 J. A.M.A. 1335 (1987).

57. The cost of care for a person with HIV/AIDS may not be covered by the person's employee benefits plan. Increasingly, employers are switching to self-insured plans and are placing a cap on lifetime benefits paid to persons with HIV/AIDS. For a discussion as to the legality of this HIV/AIDS specific cap, see Smith, *supra* note 6, at 43-46.

58. Individuals whose employers employ 20 or more persons must, according to the Consolidated Omnibus Reconciliation Act of 1985 ("COBRA"), continue their group health benefits for a minimum of 18 months. In December 1989, COBRA was amended to provide that a person who was "disabled" as of the "qualifying event" (*e.g.*, termination from employment, reduction of hours) would be eligible for an additional 11 months of continuation coverage. Certainly, one found disabled for purposes of receiving social security disability would meet this definition of disability. Therefore, persons applying for social security disability should be aware that the date of their onset of disability "reaches back" to the time of the "qualifying event". Moreover, persons eligible for 29 months of coverage (18 months plus 11 additional months for disabled persons) are also eligible for medicare, once they have received disability benefits continuously for 24 months.

crease in disposable income may also necessitate one's finding less expensive living arrangements (often in a less desirable part of town), and searching for new roommates to cut expenses. There is usually no means to boost a paltry income except by cashing in on one's life insurance policy.[59]

Persons married to someone with HIV disease could face numerous economic difficulties that might require drastic solutions. To preserve the assets of the family, individuals with HIV disease might consider transferring their assets so that they can become eligible for public aid.[60] Furthermore, spouses are responsible for the debts of each other.[61] Thus, HIV negative spouse A is responsible for the debts of HIV positive spouse B who is too sick to work. Consequently, spouse A who is working, is exclusively responsible for the mortgage payments on the house (which formerly both spouses

59. A growing number of insurance companies and other corporations are buying life insurance policies to make cash available to indigent HIV positive persons. Lewin, *Terminally Ill Can Collect Death Payout While Alive*, N.Y. Times, Jan. 27, 1990, at 1, col. 3; *U.S. Firms Eyeing Possibility of Paying Pre-Death Benefits To People With AIDS*, AIDS POL'Y & L., Mar. 8, 1989, at 1, col. 1. Accelerated death-benefit policies are relatively new and have only been sold in the United States since 1987. *See generally* Sloane, *New Policies Let Critically Ill Collect On Life Insurance*, N.Y. Times, Aug. 12, 1989, at 16, col. 4. There are generally three types of accelerated death benefit policies: a) types that pay a percentage of the face value, typically up to 30 percent, and those with a specified critical illness; after this money is disbursed, the policy's death benefits and cash value decline accordingly; b) types that pay a percentage of the face value to policyholders with any diagnosed terminal illness; c) long term care policies which generally provide accelerated benefits when a person enters a nursing home. *Id.* Typically, the corporation requires that the existing life insurance policy has been in effect for at least two years, which carries it past any contestability period, all premiums have been paid to date, the insured is mentally competent, and the insured has a life expectancy of two years or less. *Id.* The purchase price is often up to 65% of the face amount of the policy. *Id.*

60. Under many welfare programs, the transfer of assets for the purpose of qualifying for benefits is prohibited. *See, e.g.*, ILL. REV. STAT. ch. 23, paras. 3-1.3, 4-1.11, 5-2.1, 6-1.10, 7-1.5 (1987 and 1990 West Supp). The Illinois Department of Public Aid ("IDPA") will deny Medicaid eligibility to any institutionalized person who has transferred any asset, including a residence, for less than fair market value within the 30 months prior to application for medical assistance. Transfer of a home, however, does not preclude Medicaid eligibility if it was transferred to: a) the spouse; b) a dependent or disabled child; c) a sibling with an equity interest who had resided in the home for one year prior to the applicant's admission to the medical institution, or d) the son or daughter of the individual who had lived in the home for two years prior to the institutionalization and who had cared for the individual. In addition, no transfer of any asset will preclude Medicaid eligibility if: a) the asset was transferred to the spouse of a blind or disabled child; b) a satisfactory showing is made to IDPA that the individual intended to dispose of the asset either at fair market value, or the asset was transferred exclusively for a purpose other than to qualify for medical assistance; or c) IDPA determines that denial of eligibility would work an undue hardship.

61. As already noted, however, domestic partners are not responsible for the debts of the other domestic partner. *See supra* note 1. However, according to the San Francisco Domestic Partnership Ordinance, domestic partners are responsible for each other's food and housing expenses.

shared), maintainance of the insurance premiums so the HIV positive spouse and the family remains insured,[62] and for the substantial debts (mainly hospital bills) of spouse B. If spouse A is, or becomes unable to meet these financial obligations, he or she will need to consider applying for bankruptcy, transferring assets, and getting a divorce (for the sole purpose of avoiding financial responsibility for spouse B's debts).

If spouse A does not consider bankruptcy, spouse B's creditors could get a judgment against spouse B, then proceed to put a lien on the equity interest in the marital home[63] or garnish spouse A's wages. In addition, the care for people with HIV/AIDS who become incompetent may create financial liability for family members other than the spouse.[64]

E. Counseling Issues Regarding Reproductive Options for the HIV Impacted Family & Legal Ramifications for the Attending Physician

After learning of a woman's HIV status, physicians should counsel women of child bearing years about pregnancy, the likelihood of HIV transmission to the fetus,[65] and the availability of an

62. Insurance assistance programs ("IAPs") have been passed in Connecticut, Maryland, Michigan, Minnesota, and Washington. IAPs authorize the state to pay insurance premiums for unemployed persons with HIV/AIDS so they can remain insured *and* defer their Medicaid eligibility. *See generally* MD. CODE ANN. § 15-202 (Supp. 1990); WASH. REV. CODE ANN. tit. 70, ch. 70.24.440 (Supp. 1990); *Minnesota Okays Program Allowing State To Pay Insurance Premiums*, AIDS POL'Y & L., at 7, col. 1.

States wish to defer the economic impact of persons becoming Medicaid eligible. For example, New York officials estimate that with an IAP, about 1,800 persons will be assisted annually at a cost to the state and local districts of $2 million each. Approximately $26.3 million ($15.3 million federal share, $5.65 million state share, and $5.65 million local share) in medicaid expenditures will be avoided. Memorandum, re: An Act to Amend the Social Services Law in Relation to Payment of Insurance Costs for Persons with AIDS (available from the Council or from William Martin, Office of Management and Budget, New York, New York).

63. Filing for bankruptcy creates an automatic stay which operates to halt most collection activities, foreclosures, repossessions, and civil proceedings. *See generally* Schmidt, *Debtor's Rights*, NATIONAL LAWYERS GUILD AIDS NETWORK, AIDS PRACTICE MANUAL 7-14 (1991) (the chapter contains an excellent discussion of an HIV positive debtor's rights). Where property is jointly owned, the trustee has the power to sell the property. *Id.* at 7-18. The co-owner has a first right of purchase at the price otherwise obtainable by the trustee. *Id.*

64. *See Note*, *supra* note 44, at 1042 n.58. In at least 30 jurisdictions, parents are financially responsible for their incompetent adult offspring who are unable to pay for needed medical treatment. *Id.* (citing Moore, *Parents' Support Obligations To Their Adult Children*, 19 AKRON L. REV. 183, 184 (1985)).

65. Physicians should explain that there is about a 30% chance that a child born to an HIV positive mother will be HIV positive. From the time of birth, however, until the child is at least 18 months old, the child carries maternal antibodies. *See* Blanche, Rouziouz, Moscato, Veber, Mayaux, Jacomet, Tricoire, Deville, Vial, Firtion, De Crepy, Douard, Robin, Courpotin, Ciraru-Vigneron,

abortion.[66] Where possible, this information should also be shared with the woman's significant other or spouse.[67] A certain percentage of women will certainly take the risk that their children will be

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Le Deist & Griscelli, *A Prospective Study of Infants Born To Women Seropositive For Human Immunodeficiency Virus Type 1*, 320 NEW ENG. J. MED. 1643 (1989).

66. Discussing the availability of an abortion is not to suggest that physicians should recommend abortion. The physician, however, does need to discuss abortion as an option if only to limit the physician's liability for subsequent tort suits brought by the parents. This apparent obligation of a physician is significantly complicated by the Supreme Court's decision, *Rust v. Sullivan*, if the physician works for a federally-funded clinic. Rust v. Sullivan, 111 S. Ct. 1759 (1991).

HIV positive women who wish to obtain abortions might have difficulty obtaining one. *See generally* Rosenthal, *Abortions Often Denied To Women With AIDS Virus*, N.Y. Times, Oct. 23, 1990, at A16, col. 1. In a study conducted by the New York Commission on Human Rights, investigators posing as patients called 50 health centers that offer abortions and made appointments for abortions. *Id.* After being told that the patient was HIV positive, 20 of the clinics cancelled the appointments. *Id.*

67. Sharing such information assumes that one party knows the other's HIV status. Such may not be the case, and one party may not want another to know of his or her HIV status. Although this seemingly presents a dilemma, a growing number of state statutes and case law would support physician disclosure to a spouse or significant other about the patient's HIV status. For state statutes permitting such disclosure, see generally HAW. REV. STAT. § 325-101(a)(allows disclosure with consent to specified persons); ILL. REV. STAT. ch. 111 1/2, para. 780 (West 1990)(provides that a physician may disclose the HIV test results to the patient's spouse "provided that the physician has first sought unsuccessfully to persuade the patient to notify the spouse, or that, a reasonable time after the patient has agreed to make the notification, the physician has reason to believe that the patient has not provided the notification." This Illinois statute does not regulate disclosure to a significant other/domestic partner; presumably, the permissibility of such disclosures would be regulated by common law decisions); MASS. ANN. LAWS, ch. 111, § 70F (Law Co-op Supp. 1990)(requires consent for any release); MO. ANN. STAT. § 191.656(2)(Vernon 1991 Supp.)(allows for notification of spouse without consent); N.J. STAT. ANN. § 26:5C-8 (allows for disclosure with consent); N.M. STAT. ANN. § 24-2B-6 (1989 Supp.)(allows for disclosure with consent); OHIO REV. CODE ANN. § 3701.243 (allows for disclosure to sexual partner without consent); PA. STAT. ANN. tit. 35, § 521.15 (allows for disclosure without consent); VA. CODE ANN. §§ 32.1-36.1 (1991 Supp.)(allows for disclosure to spouse without consent). For an excellent discussion of the dilemma surrounding the duty to warn or notify, *see generally* Closen & Isaacman, *The Duty To Notify Private Third Parties of The Risks of HIV Infection*, 21 J. HEALTH & HOSP. L. 295 (November 1988)(authors suggest that several steps should be taken before considering any disclosure, namely: the provider must ascertain the HIV status of the patient (including appropriate confirmatory tests); the patient's current and potential sexual contacts should be identified and noted in the medical record (to properly document forseeable sexual contacts); the patient must be counseled as to the transmissibility of HIV and the methods used to prevent transmission, and this information should be documented in the medical record; attempts should be made to encourage the patient to make appropriate disclosures in face-to-face meetings with sexual or needle sharing contacts; the health care provider should independently assess the trustworthiness of the patient's willingness to inform sexual and needle sharing partners of his HIV status; if the patient will not make the disclosure, or is not trusted to make the disclosure, the health provider may consider disclosure, particularly with non-patient identifying information).

born HIV negative.[68] Physicians should share this information with both parties for many critical legal,[69] if not ethical, reasons.[70] In light of the growing number of suits for wrongful life[71] and wrongful birth,[72] parents need to give informed consent as to whether

68. HIV positive women, just as other women, still have parental urges to bear offspring. It is not uncommon for HIV positive women who have already borne HIV positive children to attempt to become pregnant with the hope of delivering HIV negative or healthy children. *See generally* Centers for Disease Control, NATIONAL CONFERENCE ON THE PREVENTION OF HIV INFECTION AND AIDS AMONG RACIAL AND ETHNIC MINORITIES IN THE UNITED STATES, Washington, D.C., August 15-17, 1988 (unpublished materials available from Centers for Disease Control) (HIV positive women are faced with the loss of the opportunity to conceive a child).

69. *See infra* notes 71-73 for a discussion of the wide variety of tort claims a physician may face, including tort suits for wrongful birth and wrongful life, for failure to make certain disclosures to both parents.

70. It is important to realize that legal duties are not necessarily coextensive with ethical duties. *But see* ABA AIDS COORDINATING COMM., AIDS: THE LEGAL ISSUES 63 (1988) (Discussion Draft)(professional ethical obligations may become legally enforceable obligations if they constitute the standard of care against which professional regulatory boards or juries, deciding malpractice claims, measure a provider's conduct).

Professional associations, such as the American Medical Association ("AMA") or the American Dental Association ("ADA"), have imposed standards which could be more restrictive than those imposed by the courts. *See* Altman, *U.S. Experts Try To Estimate AIDS Infections By Doctors*, N.Y. Times, Feb. 7, 1991, at A10, col. 5 (AMA and ADA policy promulgated in January 1991 said that any HIV positive members should either warn patients about their condition or not perform surgery); AMA STATEMENT ON HIV INFECTED PHYSICIANS, Jan. 17, 1991 (available from the Council)(policy statement of the AMA actually reads: "HIV infected physicians should either abstain from performing invasive procedures which pose an *identifiable* risk of transmission or disclose their sero-positive status prior to performing a procedure and proceed only if there is informed consent.")(emphasis added). Whether the professions can impose the aforementioned duties on HIV positive dentists and physicians may depend on the level of risk to the patient that is considered "acceptable." In weighing such risks, at least where contagious diseases are concerned, the Supreme Court adopted a "significant risk" standard. *See* Arline v. School Bd. of Nassau County, 480 U.S. 273, *reh'g denied*, 481 U.S. 1024 (1987). According to the Supreme Court, "[a] person who poses a significant risk of communicating an infectious disease to others in the workplace will not be otherwise qualified for his or her job if reasonable accommodations will not eliminate that risk." *Id.* at 287 n.16. It remains to be seen whether courts will adopt this standard in situations involving alleged risks of HIV transmission by health care providers.

71. Wrongful life suits are suits brought by children against physicians in which children essentially allege that they should never have been born. Wrongful life suits are only recognized in a few states. *See, e.g.*, Harbeson v. Parke-Davis, 98 Wash. 2d 460, 656 P.2d 483 (1983); Turpin v. Sortini, 31 Cal.3d 220, 643 P.2d 954 (1982). Most courts considering the issue have overwhelmingly rejected suits for wrongful life. *See* Elliott v. Brown, 361 So.2d 546 (Alabama 1982); Speck v. Finegold, 439 A.2d 110, 497 Pa. 77 (1981); Phillips v. United States, 508 F. Supp. 537 (S.C. 1980); Nelson v. Krusen, 678 S.W.2d 918 (Tex. 1984); James G. v. Caserta, 332 S.E.2d 872 (1985)(W. Va. 1985); Beardsley v. Wierdsma, 650 P.2d 288 (Wyo. 1982); Berman v. Allan, 404 A.2d 8, 80 N.J. 421 (1979).

72. Wrongful birth suits are brought by the parents of a defective child against physicians, the parents alleging that the child should not have been born. *See generally Wrongful Life: A Cause of Action in Search of a Theoreti-*

they wish to continue the pregnancy. For consent to be informed, physicians must explain to the parents the possibilities of HIV transmission to the fetus.

Pregnancy also has critical implications for fathers. More specifically, fathers, who may be held financially responsible for their children's care, should arguably also participate in decisions affecting this welfare. For example, if only a woman is counseled about her chance of having a child with HIV/AIDS and the child acquires HIV/AIDS prenatally, the father could bring a claim against the physician for wrongful birth.[73]

Legal Issues Arising from A Physician's "Failure to Diagnose"

Very few physicians treat persons with HIV/AIDS, and this may be, in part, because a growing number of physicians simply do not want to treat such persons.[74] This author suspects that physicians are not sufficiently knowledgeable about HIV/AIDS because they do not perceive their patients as being at risk for acquiring HIV because the physician does not treat gays and lesbians, African-Americans, Hispanics, prostitutes or intravenous drug users.[75] Physicians who are not knowledgeable about HIV/AIDS will often

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cal Basis, 20 HOSP. L. 1 (1987). In such actions, parents recover extra-ordinary expenses associated with raising a deformed child, a child the parents would not have chosen to carry to term if they had been informed of the possibility of birth defects. *Id.* at 5. The majority of jurisdictions recognize a cause of action for wrongful birth. *Id.*

73. Physicians may also face numerous other types of HIV/AIDS-related malpractice suits, such as the failure to diagnose. Such suits might also be accompanied by claims for intentional or negligent infliction of emotional distress. The author is aware of several physicians who have erroneously told patients that they were HIV positive before obtaining a confirmatory Western Blot test.

74. For articles discussing the reluctance of health care professionals to treat persons with HIV/AIDS, *see generally* DiAngelis, Martens, Little & Hastreiter, *Infection Control Practices Of Minnesota Dentists: Changes During 1 year*, 118 J. AM. DENTAL ASSOC. 299 (Mar. 1989) (in a study reported in 1986, 23 percent of Minnesota dentists responding to a survey indicated they would treat patients with AIDS; in 1987, willingness to treat persons with HIV/AIDS apparently increased to 38 percent); Moretti, Ayer & Derefinko, *Attitudes and Practices of Dentists Regarding HIV Patients and Infection Control*, 37 GEN. DENTISTRY 144 (Mar.-Apr. 1989)(in 1987, 68 percent of Chicago dentists expressed willingness to treat asymptomatic patients with HIV infection, but only 44 percent would willingly treat a patient with ARC/AIDS); Sadowsky & Kunzel, *Are You Willing to Treat AIDS Patients?*, 122 J. AM. DENTAL A. 29 (Feb. 1991) (study showed that sixty percent of general dentists in the U.S. were willing to treat persons with HIV infection).

75. Many health care professionals do not want to treat persons in groups disproportionately affected by HIV/AIDS. *See* Scott, *Many New Doctors Won't Treat AIDS, Study Finds*, L.A. Times, June 24, 1990, at 24, col. 5 (study of over 1000 residents in internal medicine showed that sixty-three percent were not planning to treat persons with HIV/AIDS; the main determinant for this unwillingness to treat was the "young physicians' attitudes and prejudices toward gay men, members of minority groups and IV drug users").

be unable to diagnose the condition, particularly in groups not perceived to be at risk for acquiring HIV or in women.

Women's HIV/AIDS infections are probably not properly diagnosed because HIV positive women often have non-specific symptoms, such as pelvic inflammatory disease or candida ("yeast") infections, which are particularly resistant to treatment. These symptoms are not the hallmark symptoms of HIV/AIDS, and include diarrhea, enlarged lymph glands, thrush, weight loss and fatigue. Unless physicians are educated as to the existence of symptoms specific to women, women will not be properly diagnosed. The failure to diagnose has critical implications, the most serious of which is a decreased life expectancy. For example, early intervention with AZT ("zydovudine") is believed to delay the onset of AIDS in HIV positive persons and is shown to prolong life expectancy three times longer after a person is diagnosed with AIDS.[76] There is some data to suggest, however, that AZT may not be an effective therapy for minorities.[77]

The failure to properly diagnose women with HIV/AIDS also affects their eligiblity for social security benefits, often a substantial portion of their income necessary for their survival. Currently, there is widespread pressure against the Social Security Administration ("SSA") in an attempt to get the SSA to adopt a more expanded definiton than that currently utilized, namely the Centers for Disease Control ("CDC") Surveillance Definition for AIDS, a definition which excludes the symptoms of women with AIDS. This pressure is being applied via demonstrations of the AIDS Coalition to Unleash Power ("ACT-UP"),[78] various congressional bills[79] and class action lawsuits.[80] Presumably, all of this pressure

76. *See* Smith, *Dickens Revisited*, *supra* note 6, at 49 n.84.

77. Very recent evidence suggests that AZT is not particularly effective in the treatment of Blacks and Hispanics. Kolata, *Federal Study Questions Ability Of the Drug AZT to Delay AIDS*, N.Y. Times, Feb. 15, 1991, at 1, col. 1 (a study conducted by researchers at the Department of Veterans Affairs found that there was little slowing in the development of AIDS symptoms in black and Hispanic patients taking AZT; the study also showed these groups fared no better when they took AZT after developing symptoms). The above data indicates that minorities should be recruited to participate in other drug trials investigating the effectiveness of drugs in treating HIV infection. This author is anecdotally aware that monolingual Hispanics have been denied access to certain drug trials because the site at which the trial was conducted did not have a translator.

78. For a discussion of the history of ACT-UP and some of their accomplishments, see generally Smith, *Dickens Revisited*, *supra* note 6, at 51-52.

79. A legislative package of 22 bills, introduced into the U.S. House and Senate February 28, 1991, deals with a vast array of women's health issues. O'Neill, *Omnibus Women's Health Bill Returns: Multi-Faceted Measure Would Address Cancer and AIDS in Women*, Windy City Times, Mar. 7, 1991, at 4, col. 1. The bill introduced into the House of Representatives is H.B. 1161 sponsored by Rep. Schroeder, and the bill introduced into the Senate is S.B. 514 sponsored by Sen. Mikulski; the short title of the proposed bill is "Women's Health Equity Act of 1991" [hereinafter "WHEA"]. *Id.* Several subtitles of WHEA deal with

has had some effect, since the SSA will be promulgating an HIV/AIDS "listing."[81]

HIV/AIDS issues, including: funding for research into the transmission, development and treatment of HIV in women (Title I, Subtitle H of the WHEA); the expansion of clinical drug trials in women (Title I, Subtitle B of the WHEA); a provision for children and transportation for women participating in medical trials (Title I, Subtitle B of the WHEA); and, authorization of funds for HIV prevention/education through family planning clinics (Title I, Subtitle E of the WHEA). *Id.* at cols. 3-4.

Subtitle H of the WHEA is called "Women and AIDS Research Initiative." This subtitle authorizes additional research funds to the National Institute of Health and the Alcohol, Drug Abuse and Mental Health Administration (Subtitle H, WHEA, Sec. 172 amending 42 U.S.C. § 300c-11 *et. seq.*). This subtitle also expands clinical trials of AIDS treatment, as established by the Community Based Clinical Research Initiative (P.C. 100-607), to include women. Further funding for transportation and child care would be provided in order to facilitate participation of low-income women in these trials (Subtitle H, WHEA, Sec. 173(b) amending 42 U.S.C. § 300c-11 *et. seq.*). This bill would also indirectly influence the CDC to broaden their AIDS definition to include the unique symptomatology of women who are HIV positive. *See also* Navarro, *Dated AIDS Definition Keeps Benefits From Many Patients*, July 8, 1991, at A!, col. 4 (estimates are that 140,000 additional people nationwide, including women and children, may be diagnosed with AIDS if the current CDC Surveillance definition is expanded).

There are no set procedures as to how the SSA should determine the legitimacy of an applicant's AIDS status, but generally they confirm the diagnosis according to the CDC definition of AIDS, which includes a list of common indicant symptoms. However, women, children and IV drug users with the AIDS virus are often denied SSI benefits because their symptoms are not included in the CDC definition. According to the CWPS, 65 percent of HIV positive women are dying from HIV-related infections that the CDC does not acknowledge. Furthermore, women with AIDS are dying four to six times faster than men.

May 9, 1991, Rep. Matsui (D-Cal.) sponsored H.R. 2299, the Social Security and SSI AIDS Disability Act. H.R. 2299, 102d Cong., 1st Sess. (1991). The Act mandates that there be an AIDS Disability Advisory Panel to address, analyze and report on additional criteria needed in the current evaluation of social security claims by individuals with HIV/AIDS. *Id.* § 2(c)(1)(A). More specifically, the aforementioned panel is charged with developing recommendations regarding the extent to which HIV infection in women, children and IV drug users should be used to establish disability in determining eligibility for social security benefits. *Id.*, § 2(c)(1)(B). The Act mandates that the panel submit a report within 180 days after convening; not later than 180 days after the panel's report is submitted, the Secretary of DHHS must submit to Congress recommendations for legislation, based on the panel's report. *Id.* § 3(a)(1).

80. *See* S.P. v. Sullivan, AIDS POL'Y & L., Oct. 17, 1990, at 1, col.1 (S.D.N.Y. 1990), (class action requests the Court to order the DHHS to pay presumptive benefits for any claimants with proof of HIV infection and to obtain a report from a treating physician showing inability to work; to tell benefits adjudicators in New York that current standards are underinclusive and to inform them of the nature of HIV-related disability; to set up a determination system that would allow full development of medical and nonmedical evidence for claimants submitting proof of HIV seropositivity and alleged inability to work; to issue a proposed regulation for evaluating HIV-related disability within 90 days; and to reopen past cases on an expedited basis).

81. The SSA is currently developing a notice of proposed rulemaking which will detail revised evaluation criteria for assessing HIV/AIDS disability claims. Letter from Lawrence Keillor (Metro Public Affairs Specialist, SSA) to James Monroe Smith (March 13, 1991)(available from the Council).

F. Insurance Issues for the HIV Affected Family

Families in which one parent is HIV positive, particularly if this parent is the prime or sole wage earner, will have difficulty obtaining insurance. To the extent that the family is dropped from insurance,[82] the family's ability to get insurance may depend upon whether the state has an insurance risk pool.[83]

HIV Testing Issues

This author suspects that ultimately insurance companies will seek the HIV status of both spouses even in deciding whether to insure the spouse who tested HIV negative.[84] For example, consider the situation in which one spouse is HIV positive but the HIV negative spouse seeks an insurance policy. Assuming that the couple does not engage in "safer sex,"[85] it is possible that the HIV negative spouse will ultimately become HIV positive during the policy's duration.

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82. A family who is insured through group insurance might be dropped from insurance if the insurance company which underwrites the group policy either stops underwriting group insurance or stops underwriting the policy for the employer. No law mandates that an insurance company offer group insurance to a particular employer for a period of time.

Illinois has passed a law which addresses the problems raised by the group insurance crisis. *See* ILL. REV. STAT. ch. 73, para. 979(i) (West Supp. 1990). This law precludes employed individuals from being denied group insurance merely because they have a pre-existing condition. The statute states:

> [i]n the event a discontinued policy is replaced by another group policy, the prior insurer or plan shall be liable only to the extent of its accrued liabilities and extension of benefits. Persons eligible for coverage under the succeeding insurer's plan or policy shall, until such time as such person becomes eligible, be covered by the succeeding insurer's policy in such a way as to ensure that such persons shall be treated no less favorably than had the change in insurers not occurred.

Id.

83. Numerous states have passed laws, commonly referred to as insurance risk pools, in which the state offers insurance to otherwise uninsurable persons (such as HIV positive persons) and the state pays a portion of the individual's health insurance premium. *See generally* Comprehensive Health Ins. Plan Act, ILL. REV. STAT. ch. 73, paras. 1301-14 (1987).

84. The Council is currently representing a person who was denied life insurance because his roommate is HIV positive. Although the applicant himself is HIV negative, the insurance company found him uninsurable. The insurance company's discrimination is being challenged on several legal grounds: information about one person was unlawfully used to deny insurance to a second person; the stated reason for refusal to insure is not related to life expectancy and is not an actuarily sound classification; and, the insurance company violated anti-discrimination laws.

85. *See* COHEN, *Safe Sex, Safer Sex, and Prevention of HIV Infection*, AIDS KNOWLEDGE BASE § 11.1.4 (Cohen, Sande & Volberding eds. 1990).

G. Care Issues for the HIV Affected Family

Symptomatic HIV positive parents may have difficulty caring for their children. In general, HIV positive women who are the sole custodians of their children report day care and respite care as largely unmet needs.[86] The HIV negative spouse, on the other hand, may have difficulty caring for the spouse with HIV/AIDS. It may be necessary to find home-based care for this spouse. If the spouse suffers from HIV dementia, it may be necessary to arrange full time care for the spouse. Ultimately, the family may need to explore possibilities for more chronic long term care, such as is available in a nursing home.[87]

Although care issues may not present numerous legal problems,[88] lawyers must be aware of them since they are a critical issue to HIV-affected families (frequently because they are a source of great stress). For a lawyer to counsel clients effectively and empathically, it is important to understand all the stresses they face.

H. Confidentiality in HIV-Affected Families

Caregivers for many HIV positive persons are their families.[89] However, because of the stigma associated with HIV infection, many HIV positive persons do not want their families to know of

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86. Carr, *Needs Assessment*, *supra* note 3, at 28-30.

87. Nursing home care is infrequently covered by most health care insurance policies; most are often limited to in-hospital care. This author is anecdotally aware, however, that some insurance companies have paid for nursing home care after HIV/AIDS advocates have pointed out that such latter care is drastically less expensive than hospital care.

Nursing homes have been exceedingly reluctant to admit persons with HIV/AIDS. This is attributed to the fear that if the nursing home admits persons with HIV/AIDS the nursing home will lose their coworkers and private pay patients. Due to the reluctance of nursing homes to accept persons with HIV/AIDS, the IDPA initiated a program in March 1989, the "Inappropriate Level of Care Project," which allowed hospitals documenting at least five unsuccessful attempts to place a patient in an appropriate nursing home facility, to become eligible for enhanced Medicaid reimbursement for hospital-based care. INFORMATIONAL NOTICE FROM THE IDPA ON THE "INAPPROPRIATE LEVEL OF CARE" PROJECT TO PARTICIPATING HOSPITALS, CHIEF EXECUTIVE OFFICERS, CHIEF FINANCIAL OFFICERS, AND PATIENT ACCOUNT MANAGERS, Feb. 23, 1989 (available from the Council).

Nursing home care, however, is only one type amidst a complex continuum of care that persons with HIV/AIDS will require. Although some health insurance plans exclude coverage for home health care, some states, including New York, now mandate that such coverage be offered. SCHERZER, *Insurance And Employee Benefits*, AIDS PRACTICE MANUAL 8-15 (*citing* N.Y. INS. LAW §§ 3216(j)(2), 3221(k)(1)(A) (McKinney 1985)).

88. A symptomatic HIV positive parent's ability to care for a child may be called into question, however, by state child care agencies. Such agencies might allege child neglect.

89. *See generally* KIRKPATRICK, AIDS, SHARING THE PAIN: A GUIDE FOR CAREGIVERS (1990).

their condition. Consequently, upon being discharged from the hospital, HIV positive persons have requested that discharge planners refrain from informing the patient's caregiver of his or her HIV status.

The above scenario poses a dilemma to the extent that caregivers, who may become as involved as health care professionals in caring for the individual with HIV disease, are not put on notice that they may need to adhere to certain precautions.[90] For example, when in contact with "weeping dermatitis" the caregiver may need to wear gloves.

Confidentiality is not an absolute, but rather involves a balancing of the caretaker's need for disclosure (in this instance, to enable to caregiver to take appropriate precautions in certain circumstances) with the HIV positive persons' reasons against disclosure (privacy interest in not disclosing a stigmatizing status). When it can be ascertained that the caretaker has a legitimate "need to know"[91] the family member's HIV status, then disclosure should be allowed.

CONCLUSION

As HIV positive clients or HIV negative individuals in HIV-affected families seek legal advice, attorneys must appreciate the physical and psychological stress these clients are experiencing. Such individuals may be irrational and/or in various stages of denial. They may be frustrated and/or depressed (probably both). They will most likely be desperate and, consequently, will want fast assistance and fast answers; daily they face health care professionals who cannot give them concrete answers (most drugs are still in

90. Institutions which do not make disclosures of a patient's HIV status to the appropriate nonprofessional caregivers (e.g., family members), therefore, could face liability for failure to disclose the patient's HIV status. Such disclosure issues will largely be confined to situations in which the caregiver is being placed at a substantial risk of acquiring HIV. *But see* Leckelt v. Bd. of Comm'rs, 909 F.2d 820 (5th Cir. 1990)(court focuses on the fact that an HIV positive health care worker who engages in noninvasive procedures created a "potential" opportunity for HIV transmission to patients).

91. In assessing "need to know," the author finds that it is helpful to look to the purpose for disclosing confidential information. For example, a nurse working with an HIV positive patient arguably has a need to know a patient's HIV status so the nurse is better equipped to meet the medical and psychological needs of the patient. A nurse working in the same hospital, but who does not care for a particular patient, does not need to know that patient's HIV status. A hospital social worker also has a need to know which clients he serves are HIV positive, so the social worker can inform clients of appropriate HIV/AIDS-specific services (both during the hospital stay and upon discharge) available to the client. In general, a health care or service provider only has a need to know a client's/patient's HIV status when that information is used for more effectively serving the client, or when that information is legitimately used to protect foreseeable persons from harm.

effect "experimental"), and they may have to deal with bureaucratic, overworked institutions which may not differentiate their special problems or concerns.

Finally, HIV affected families may come to attorneys with multiple problems. When facing these problems an attorney should consider taking the path of least resistance. A little common sense certainly goes a long way. The attorney will not only be called upon to mobilize his or her legal skills, but also skills in ministering and counseling, and in social work and psychology as well.