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The Legal Needs of Women with HIV

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should be treated as such. The most important message for me in the health behavior study is that only four percent of the 483 women interviewed consider lesbians to be at risk for HIV infection. We all need to be careful about what we think our clients know about HIV infection. They may be unaware of their risks, or they may be in denial.

In the seroprevalence study, 498 women were surveyed; sixty-eight percent self-identified as lesbians, and about twenty-two percent identified as bisexual. Of the women surveyed, 1.2% were HIV-infected, which is about three times higher than in the general population of women in San Francisco County. The seroprevalence study did not document any evidence of woman-to-woman transmission. However, the study did show that the rate of high risk behavior involving drug use was fairly high. Of the women surveyed, 10.4% had used injection drugs since 1978, 3.8% had used injection drugs in the past three years, 7.4% had shared needles since 1978, and 3.2% had shared needles with gay or bisexual men. There was also evidence of high risk sexual behavior: 56.3% reported unprotected oral sex with men, 39% reported unprotected vaginal sex with men, and 10.9% reported unprotected anal sex with men. Many people assume that because a woman is gay, she is low risk for HIV, but we need to ask questions about that person’s behavior to identify other risk factors involved. This study highlights the need for increased education. The Surveillance and Prevention Branches of the Department of Public Health conducted these studies because they recognized that lesbian and bisexual women are at risk, and the surveys proved this to be true. As service providers, we need to be aware of these issues. Effective education and treatment are dependent on awareness and recognition. As I said before, we cannot help women with HIV if we do not know they are infected.

Comments by Marina T. Sarmiento:

The Legal Needs of Women with HIV

I. INTRODUCTION

I am the Outreach Director at the AIDS Legal Referral Panel. We provide legal counseling to clients throughout the Bay Area. Since I took
the position in March 1993, I have seen both an increase in the number of women requesting services and a definite pattern in their legal needs.

Historically, women with HIV have been less likely than men to seek legal services. Approximately fifty to seventy percent of the clients we serve at the AIDS Legal Referral Panel are men. This is true for a number of reasons. First, men often feel a greater sense of entitlement to legal services. Women, however, tend not to contact us unless they are already connected to a support network. Often, women are referred to us by a social worker who makes the initial phone call for the client.

Second, many women who would like to obtain legal assistance are unable to make an appointment for legal counseling because they are the primary caretakers of one or more children and are unable to find child care.

Finally, women are less likely to seek legal assistance for HIV-related concerns because they often do not discover that they have HIV until they are in the later stages of AIDS. Many women are unable to see a doctor because they do not have health insurance or are too busy caring for their children. Therefore, they may not receive an early diagnosis or subsequent treatment. Even those women who do receive regular health care may not be properly diagnosed. Historically, HIV/AIDS has been medically defined based on opportunistic infections as they have appeared in gay men. The Centers for Disease Control (CDC) definition of AIDS has been changed recently to include more diseases particular to women. However, more of the AIDS-related symptoms found in women should be included.

The number of women with HIV is increasing. According to the Centers for Disease Control, AIDS was the fourth leading cause of death for women aged twenty-five to forty-four in the United States in 1992. As the number of women with HIV grows, so will the demand for legal services. It is important for the legal community to be aware of the issues facing women with HIV so we can properly advise women on how to legally protect themselves, their children, and their partners.

II. WILLS

A will is a legal document that governs how property and assets will be distributed upon an individual's death. People who are poor often think that they do not need a will because they do not have many assets. How-

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2 CDC Reports HIV Disease No.1 in Young Adults’ 1992 Deaths, AIDS POLICY & LAW, Nov. 12, 1993, at 5.
ever, there are several reasons why a will is strongly advised for women with HIV.

When a person dies without a valid will, her property passes by intestate succession to her spouse, children, and next of kin as provided by state statute. Many women who have been separated from their husbands do not realize that as long as they are still legally married their property will pass to their estranged spouse. Therefore, a woman with an estranged husband needs to have a will if she wishes to leave her property to someone else.

Similarly, a will is necessary if a woman with HIV does not want her property to go to her legal "next of kin." For example, a lesbian with HIV will need a will if she wants her lover to inherit her property. Because the lover is not a family member, she would receive nothing if the property is allowed to pass by intestate succession.

I hear horror stories all the time. There were two women living together. One died of AIDS. The survivor, an artist, made beautiful paintings for her lover. When the lover died, her family had keys and took the contents of the entire apartment, including paintings and other possessions belonging to both the lover and the survivor. A will would have ensured that the surviving partner inherited the paintings and the possessions they acquired together.

III. DURABLE POWER OF ATTORNEY FOR HEALTH CARE

Another important document for women with HIV is a Durable Power of Attorney for Health Care (DPAHC). This document allows a person to designate an agent to make medical decisions on her behalf when she becomes unable to make such decisions for herself.

In *Cruzan v. Missouri Department of Health,* the United States Supreme Court recently affirmed a patient’s right to choose whether to continue medical treatment. The Court held that an individual may choose to discontinue medical treatment even if doing so will result in death. In order to exercise this right, a patient must be competent, or have explicitly declared her wishes regarding medical treatment prior to her incapacity. The Court held that a state may require that the patient’s wishes be proven by clear and convincing evidence before allowing a surrogate to decide to discontinue treatment. The Court did not decide whether a state must give effect to the decision of a designated surrogate in the absence of an explicit statement of the patient’s wishes regarding medical treatment.

Through a Durable Power of Attorney for Health Care, a woman with HIV can designate an agent and provide evidence of her wishes regarding

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4 *Id.* at 278-79.
5 *Id.* at 284.
6 *Id.* at 287 n.12.
treatment. To execute a valid DPAHC, some basic requirements must be met. The woman must be a competent adult at the time she executes the document. She must name and specifically authorize an agent to make decisions on her behalf when she becomes incompetent. Her signature must be dated and witnessed by two individuals or be notarized by a notary public. If a printed form is used, the document must contain a warning statement with language specified by state statute. This requirement is designed to inform and protect those executing a DPAHC without the advice or assistance of legal counsel. A valid DPAHC takes effect when the patient is no longer capable of making informed decisions regarding medical treatment.

A woman with HIV can use a DPAHC to authorize her agent to have priority in visitation while she is hospitalized. Many women have lovers or friends they want to see while they are hospitalized. Without a DPAHC, lovers and friends may be barred from the hospital door by parents who are grief stricken, and who possibly never liked the lover or friend.

A DPAHC can be used to authorize an agent to decide, during a patient’s incapacitation, which doctors or hospitals to use, and whether to continue medical care, life prolonging treatment, or painkillers. The agent can exercise a patient’s right to privacy in making decisions regarding medical treatment, including the right to be left alone, even though the exercise of that right may hasten death or contravene conventional medical advice.

A DPAHC can allow an agent to have access to medical and personal information and to receive items of personal property that would otherwise be released only to family members. The agent can also authorize the release of the patient’s body from the hospital and the disposition of the remains. Finally, the agent can make arrangements for a funeral or memorial service in accordance with the patient’s stated wishes.

IV. Guardianship

The Journal of the American Medical Association estimates that by the year 2000, 82,000 children will be orphaned by AIDS. AIDS is changing the make-up of the American family. Some children orphaned by AIDS are living with relatives or friends. Others are adopted or end up in the foster care system. Still other children may end up homeless and living on the streets.

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10 Id.
Women call us most often for help in the family law area. While some women plan for the future care of their children, many do not. They may fail to plan for the future due to denial, their fear of disclosure, the lack of a potential guardian, the lack of counseling or legal advice, or inflexible laws.

Historically, women who wish to plan for their children's future usually set up a guardianship. A guardianship is a formal legal arrangement whereby an adult other than a child's parent is appointed to take care of the child. The guardian obtains legal custody and assumes all parental rights and responsibilities over the child. The guardian can make decisions regarding the child's residence, education, and medical care, as well as other decisions affecting the care, custody, and control of the child. A parent's custodial rights are suspended during the guardianship.

In the past, many women chose not to petition for a guardianship because they did not want to give up rights to their children while they were still capable of caring for them. Women were forced to choose between planning for their children's future or living day-to-day, hoping they remained healthy and that someone would volunteer to take care of the children upon their death. However, without a legal guardianship, a volunteer would not be able to make important decisions regarding the medical care, schooling, or other issues involving the child.

Some women chose to proceed with the guardianship because they trusted the guardian—often a friend or lover—to allow them to continue to be involved in the child's life. Unfortunately, some of these women are shut out by the guardian once the guardianship is executed. The guardian may decide that it is too traumatic for the children to see their ill mother, or that it is in the children's best interest to take them away from their mother before her death.

Today, in California, a terminally ill parent need not lose custodial rights when a guardian is appointed. In October of 1993, Governor Wilson signed legislation specifically geared towards making guardianships more feasible for parents with HIV and other terminal illnesses. This new law, authorizing joint guardianships, took effect on January 1, 1994.

Probate Code section 2105(f) allows the terminally-ill custodial parent and the parent's nominated guardian to be appointed as joint guardians of the child. Both adults share responsibility for the care, custody, and control of the child. This new law allows a woman with HIV to make legally enforceable plans for the future care of her children while allowing her to retain custody and control until she becomes incapacitated or passes away.

A joint guardianship is allowed only if the parent is diagnosed with a terminal illness. A doctor must execute a declaration atting that the

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15 CAL. PROB. CODE § 2105(f) (West Supp. 1994).
16 Id.
parent has an incurable and irreversible condition that, without the administration of life-sustaining treatment, will result in death within two years, based on reasonable medical judgment.

A court must find that a guardianship is necessary or convenient for the child and that the guardianship is in the child’s best interest. If a non-relative guardian is chosen over another parent, the court must also find that awarding custody to the other parent would be detrimental to the child and that awarding custody to the non-parent is in the child’s best interest.

There are several advantages to petitioning for a guardianship while the mother is still alive. First, it allows the mother greater input in choosing a guardian. Many parents think that they can effectively plan for their children by nominating a guardian in their will. However, a will must go through probate, and a judge will ultimately decide whether the nominee is an appropriate person to care for the child. If the mother has nominated a non-relative, a same-sex lover, a friend, or any other “unorthodox” choice, the judge is more likely to approve the guardianship if the mother is alive to testify on her nominee’s behalf. Otherwise, the judge could disregard the nomination and appoint a family member or someone else the mother may not have wanted as a guardian. Second, petitioning for guardianship while the mother is still alive allows her to enjoy the security of knowing who will care for her children. Third, a joint guardianship established before the death of the mother can ensure a smoother transition for the children upon the mother’s death because the guardianship automatically continues in the remaining guardian.

However, there are some disadvantages to joint guardianships. Both guardians must agree in exercising power. The guardians must jointly make decisions regarding the residence, education, health care, and other daily custody and control issues affecting the child. The new law is silent on how to resolve disputes if the guardians disagree. The guardians may have to go to court. The new law indicates that if a joint guardian becomes incapacitated or is unable to act, the remaining joint guardian can petition the court for an order to act. This is problematic in the event of a disagreement between the co-guardians, because the last thing that a woman with AIDS needs is to be in the courtroom arguing with a co-guardian.

The two-year clause in the new law’s definition of terminal illness is also an untested and potentially problematic area. Many people with HIV live much longer than two years. Can an asymptomatic woman with HIV

17 CAL. PROB. CODE § 1514 (West Supp. 1994).
18 CAL. FAM. CODE § 3041 (West 1994).
19 CAL. PROB. CODE § 2105(d) (West Supp. 1994).
20 CAL. PROB. CODE § 2105(c)(1) (West Supp. 1994).
21 CAL. PROB. CODE § 2105(e) (West Supp. 1994).
22 CAL. PROB. CODE § 2105(f) (West Supp. 1994).
who is still able to care for her children take advantage of a joint guardianship or does she fail to qualify as terminally ill? The mother may have to wait until she experiences some symptoms to file for guardianship. However, she should not wait until the end stages of AIDS due to the threat of AIDS-related dementia. I would advise mothers who are planning for their children to discuss their condition with their doctors. Some doctors may be willing to diagnose an asymptomatic HIV-positive condition as a terminal illness because, without drugs, there is a reasonable possibility that the woman will die within two years.

Despite these potential problems and ambiguities, guardianships can make a significant difference in the life of a mother with AIDS and in the lives of her children. It is very easy to set up a guardianship. If unopposed, it is approximately a two-month process involving one court appearance and possibly an appointment with family court services.

V. Conclusion

Although legal planning can benefit women with HIV tremendously, obstacles to legal services can be overwhelming and intimidating. Social workers must continue to help clients make contact with legal service providers. Attorneys need to understand the unique situation women are in as primary caretakers of children. This role affects a woman’s ability to take advantage of legal services and determines, in part, the legal services required. Attorneys need to be aware of the gender-specific factors involved in assisting women with HIV. Finally, women with HIV need to be educated regarding their basic legal rights and the tools available to assist them in planning for their future needs and those of their partners and children.