

AIDS and Changing Concepts of Family

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A FEW YEARS AGO, AFTER MY DAUGHTER'S marriage, a friend remarked that the wedding had been very unusual. "It was a first marriage," she explained, "and the parents of both the bride and groom were still married to their original partners." Pointing out that my husband and I, unlike most of our friends, had avoided the exquisitely delicate questions of etiquette that complicate the weddings of children of divorced or "blended" families, she asked, "How does it feel to be an anomaly?"

This anecdote may reveal only a glimpse of life among a certain segment of the middle class in New York City in the mid-1980s. There can be no doubt, however, that across the nation American families have changed, are changing, and will continue to change. A statistical snapshot of American families today documents the shifts. Data from the 1980 United States census show a sharp rise from the 1970 figures in the number of single-parent families, nearly all of them headed by women. Almost 20 percent of minors live with one parent, an increase from 12 percent in 1970. The number of people living alone also increased by 64 percent over the previous census. The number of unmarried couples living together almost tripled from 523,000 in 1970 to 1.56 million in 1980, and increased another 63 percent from 1980 to 1988 (U.S. Bureau of the Census 1981, 1988). In 1988, the proportion of households accounted for by married-couple families with children

under the age of 18 present in the home had declined by 13 percent since 1970 (U.S. Bureau of the Census 1988). According to the U.S. Department of Labor, by 1987, 64 percent of married mothers with children under the age of 18 were working or seeking work, compared with 30 percent twenty years earlier, and less than 10 percent in 1940 (Levitan, Belous, and Gallo 1988). As Toffler (1980, 211–12) has pointed out, “If we define the nuclear family as a working husband, housekeeping wife, and two children, and ask how many Americans still live in this type of family, the answer is astonishing: 7 percent of the total United States population.” That percentage is undoubtedly lower ten years later.

Behind these statistics lie sweeping historical, economic, scientific, and cultural trends. Families are no longer primarily units of production and procreation; they have become instead centers of emotional and social support. Procreation is separated from sexual behavior and is an act of choice rather than necessity. Women, freed from constant childbearing, may choose to enter the labor force. Since they are frequently divorced or never married and are often the sole support of their children, they may have no choice but to enter the labor force.

These statistics are only numerical representations of the extraordinary diversity of family life today. They are based on “household” composition, only one factor used to describe “family.” They do not convey the complex and varying arrangements whereby individuals create, dissolve, and recreate supportive and intimate bonds. Tolstoy’s (1981 [1877]) famous dichotomous description of families, expressed in the opening lines of *Anna Karenina*—“Happy families are all alike; every unhappy family is unhappy in its own way”—is only half true today. While the second half of the dictum is certainly valid, it is now the case that happy families are not all alike.

In this diverse and shifting milieu a major medical and social crisis encompassing AIDS and HIV disease (hereafter referred to as “AIDS” for simplicity) heightens processes of change already underway and sets in motion new, particularized responses. This article is intended to describe some of these changes and to explore their potential impact on current and future families. It is an observational, speculative, nonempirical attempt to call attention to a largely unrecognized aspect of the epidemic rather than to provide a systematic sociological, historical, or anthropological analysis.

While the subject of “family” is difficult to confine within rigid

boundaries, this article focuses on key intersections where families and societal institutions meet. At these intersections—such as medical decision making, custody decisions, and housing law—definitions of family and rights of family members are straining to accommodate the new situation of AIDS. As Donzelot (1979) pointed out in *The Policing of Families*, the family is not a “point of departure . . . a manifest reality, but . . . a moving resultant, an uncertain form whose intelligibility can only come from studying the system of relations it maintains with the sociopolitical level.” In this view families are social as well as biological constructs. In today’s world both dimensions of family are being challenged.

Who Counts as Family?

The answer to this apparently simple question is by no means easy. It depends on why the question is being asked and who is giving the answer. “Family” can be used in many ways, from the narrowest interpretation to the most metaphorical, from description to polemic. Consider the recent case of Nancy Klein, a comatose and pregnant Long Island woman. With her parents’ agreement, Mrs. Klein’s husband, Martin, sought court permission for an abortion, which doctors hoped would improve her chances of recovery. John Short, an antiabortion advocate, sought legal guardianship of Mrs. Klein and her fetus. He claimed, “We are all members of the human family. If we see someone being manipulated into killing a child, we have to step in” (*New York Times* 1989b). In this case, the metaphor of “family” was used to further a political agenda and to override the legal and ethically justifiable decision of a real-life family. The judge ruled in favor of Mr. Klein’s request, thus rejecting the claim that strangers who do not approve of medical decisions have a legal right to take decision-making power from traditional family members.

In this article I use a definition of “family” that is broad but not unlimited. If everyone counts as family, then family loses its special meaning. If only a few count as family, then our understanding of human relationships is impoverished. What separates family from friends and strangers is not just blood or legal ties but an emotional quality of relationality, continuity, and stability. Individuals are born and marry into families; they also choose to enter relationships that are family-

like, even if they are called by other names. The essential characteristics of these relationships are permanence (at least in intention); commitment to mutuality of various forms of economic, social, and emotional support; and a level of intimacy that distinguishes this bond from other, less central attachments. Thus, my working definition is: *Family members are individuals who by birth, adoption, marriage, or declared commitment share deep, personal connections and are mutually entitled to receive and obligated to provide support of various kinds to the extent possible, especially in times of need.* It is perhaps no accident that in the traditional marriage vows, the pledge to remain constant places "in sickness" before "in health"; sickness tests family strength and resiliency as few other crises do. In this context AIDS is the supreme test of family devotion.

This definition both respects traditional notions of family and recognizes nontraditional forms of commitment. Who would be excluded? People in intentionally transitory relationships; individuals who claim status as a family member solely as a convenience to obtain benefits otherwise not available; persons who by abandonment or other actions give up their claims to the benefits of family status. (While a father remains a father, no matter how he treats his child, the recognition that society gives to his status will diminish if he fails to fulfill the minimum obligations of parenthood.) This working definition will undoubtedly be problematic at the boundaries; the central core of deep, long-term, emotional commitment, however, should hold firm.

This definition has some traditional elements. Biological definitions are the most familiar (a word that itself is derived from "family," and connotes shared associations). Dictionary definitions of "family" stress the parent/child relationship. Thus, Webster's dictionary defines family as "the basic unit in society having as its nucleus two or more adults living together and cooperating in the care and rearing of their own or adopted children." Even this definition is being challenged by surrogate parenting, in which a couple commissions a woman to bear the man's child and secures her agreement to give up her maternal rights to the adoptive mother. New reproductive technologies create situations in which a child may have two different "mothers"—one who supplies the genetic material and another who gestates the fetus. It is possible to add a third mother to this complex, if still another woman raises the child.

This working definition further delineates the functional definition

offered by the Task Force on AIDS and the Family convened by the Groves Conference on Marriage and the Family:

Families should be broadly defined to include, besides the traditional biological relationships, those committed relationships between individuals which fulfill the functions of family (Anderson 1988).

Individuals may count as family members people who are unrelated to them in any traditional way; for some purposes self-definition is more important than legal ties. But public policy definitions of family, which determine eligibility for various benefits and privileges, vary considerably from self-definitions. Thus, biologically and statutorily unrelated individuals are usually not eligible for the benefits accorded to spouses and children, regardless of the depth or duration of their emotional or economic attachments.

Legislatures, courts, and governmental agencies differ in defining "family." For example, according to the U.S. Bureau of the Census (1988), "A family or family household requires the presence of at least two persons: the householder and one or more additional family members related to the householder by birth, adoption, or marriage." A householder who lives alone or exclusively with persons who are not related is defined as living in a "nonfamily household." Thus, non-traditional functional and relational coupling of two consenting and committed adults—for example, gay or lesbian couples—are by this definition specifically excluded from the designation of family.

The census bureau's definitions do not directly affect individuals' access to benefits, as do the definitions of some other agencies. There is no single, national legal definition of family; family law is administered by the states, and each state has different definitions. Moreover, definitions adopted by governmental agencies vary, with some being more restrictive than others. For example, the California corrections law limits the people who are entitled to overnight prison visitation with eligible inmates to persons who are related by blood, marriage, or adoption (City of Los Angeles Task Force on Family Diversity, 1988, 22). On the other hand, the more broadly construed New York State definition of family in the Domestic Violence Prevention Act includes "persons related by consanguinity or affinity," "persons formerly married to one another regardless of whether they still reside in the same

household," "persons who have a child in common regardless of whether such persons are married or have lived together at any time," "unrelated persons who are continually or at regular intervals living in the same household or who have lived in the past continually or at regular intervals," as well as a catch-all category of "other individuals deemed to be a victim of domestic violence as defined by the department in regulation" (New York State, Social Services Law, Section 49(2)).

Some people in nontraditional relationships, and some gay and feminist social critics, reject the term "family" because of its historical association with particular arrangements of economic, political, and sexual power that they view as oppressive. Yet the alternatives, such as "bonding groups" and "friendship networks," fail to convey the notion of deep personal connectedness that is suggested by "family." "Community" in some cases—for example, religious communities—does convey this sense, at least for its members. The word is used more commonly, however, to mean a much less central association. While it is important to recognize that family ties can constrain as well as bolster, most people share an understanding of family that suggests a special and enduring, if not necessarily happy, relationship.

As more and more people live in nontraditional arrangements, the distance between their needs and interests and official designations widens. This discrepancy is apparent in many areas, but appears with particular force in AIDS which, at the same time, heightens the summed impact and lays bare the multiple parts of dysfunctional designations and categories. Those most affected by AIDS and HIV infection—gay men, intravenous drug users and their sexual partners, largely from poor, minority communities—are also those most likely to have nontraditional living or family arrangements. Even if they lived in traditional families before they became ill, the stigma of AIDS and the stress of coping with terminal illness may have created deep intrafamilial rifts. The person with AIDS may thus have to acquire a new family for emotional and economic support. This family may be made up of some traditional family members and friends; increasingly, health care workers and volunteers for social service agencies fulfill the functions of family. In its most extreme and metaphorical version, the hospital becomes the surrogate family. "For many [babies with AIDS], Harlem Hospital is their mother and father. We're all they have," says Margaret Heagarty, M.D., director of pediatrics at the hospital (Breo

1988, 33). Dr. Heagarty, as *mater familia*, views her wards as claimants to both her relational and functional commitment.

AIDS is a catalyst in efforts to expand the definitions of "family" to reflect the reality of contemporary life. A movement to recognize "family diversity" has emerged in response to the problems experienced by members of nontraditional families, particularly some politically active gay and lesbian couples and elderly unmarried couples, in obtaining benefits such as medical insurance and bereavement leave for their "domestic partners." Starting in Los Angeles, and now spreading to other cities, the organizers call for expanded definitions of family. The City of Los Angeles Task Force on Family Diversity's (1988) final report concluded:

No legitimate secular policy is furthered by rigid adherence to a definition of family which promotes a stereotypical, if not mythical, norm. Rather, the appropriate function of lawmakers and administrators is to adopt policies and operate programs that dispel myths and acknowledge reality.

In May 1989 the City of San Francisco passed the nation's first law allowing unmarried homosexual and heterosexual couples to register publicly as "domestic partners," thus paving the way for them to obtain health benefits, hospital visitation rights, and bereavement leave. For a fee of \$35, domestic partners, defined as "two people who have chosen to share one another's lives in an intimate and committed relationship" can file a "Declaration of Domestic Partnership" (*New York Times* 1989i).

The boundaries and utility for public policy of expanding definitions of family are being tested. AIDS is stretching the boundaries and, by so doing, may change more than definitions. The structures and services of institutions may change in response to the differing arrangements that will be officially counted as "family."

Families in Crisis

AIDS throws families into crisis. Crises in family relationships are often the occasion for bringing private intrafamilial matters to the notice of social institutions that are designed to respond with services and assis-

tance. Because the two groups most seriously affected by AIDS—gay men and intravenous drug users—are generally (and often inaccurately) considered to be isolated from family life, the impact of AIDS on internal family functioning and mental health has not been fully appreciated. Public policy has barely begun to recognize the enormous future needs for mental health and social services that will be needed by persons with AIDS and by their families, however defined. Families are implementers of public policy, sometimes by design, more often by default. A public policy that reduces hospital length of stay for AIDS patients by establishing diagnosis-related groups as the basis for reimbursement assumes that discharged patients will go “home” and that families will provide care. Yet, there are few supports in place to make it possible for families to implement that policy. “Paco,” a person with HIV disease, describes this plight:

To me the problem is that I’m not getting help from anybody else. My parents are doing everything and they can’t do it all. And Social Security opens my case and they close it and they open it again (Citizens Commission on AIDS 1989).

This circumstance is not unique to AIDS. For example, there are no explicit employment or tax policies to enable adult children to care for frail, dependent, elderly parents.

Traditional families that have already developed internal ways of coping with crises may be totally unprepared for the stress created by external pressures, such as stigma. Whether the response is rejection or acceptance, as Gary Lloyd (1988), a sociologist of the family, states:

Families with a member discovered to have HIV infection or diagnosed with AIDS will experience high levels of stress, and disruption in all areas of family life.

Some families, however, react by mobilizing to fight the stigma and are able to transcend their initial fears and prejudices. They may speak publicly about the disease, raise money for research and care, and become advocates for their ill family member and all those affected. One suburban family with seven children was transformed by the experience of caring for a dying gay son; the mother became less concerned with other people’s opinions; a sister became politically active; a son who is

a physician altered the way he cared for his patients (Tiblier, Walker, and Rolland 1989).

Cultural or religious differences may affect family views. For example, some families have deeply held views against homosexuality or drug use. Nevertheless, in black families a tradition that reveres the mother/child bond may transcend negative attitudes toward these behaviors. Mildred Pearson, a black woman whose son Bruce died of AIDS in 1987, says: "He was a wonderful son. My son was gay. I didn't like that, but he was. He did not leave me any babies or a whole lot of money, but he left me his strength. My son died with dignity" (*New York Times* 1988).

Some Hispanic families, imbued with the concept of *familismo*, accept responsibilities of care for their sick family member, but may be wary of accepting the help of outsiders such as social workers. A counselor in Chicago says, "Latino people are hiding their children and loved ones with AIDS." Part of their reluctance is based on unsatisfactory experiences with non-Spanish-speaking health care workers and, in some cases, a fear of discovery of illegal entry into this country. In addition, many Hispanic families have a deep distrust of doctors and the medical system (*Chicago Tribune* 1987; Nelson Fernandez, personal communication).

Abandonment by families of their sick or disgraced members is a familiar theme in life and literature. Silas, the hired man in Robert Frost's (1971 [1914]) poem "The Death of the Hired Man," goes back to Warren and Mary, his employers, to die. Warren asks his wife: "Silas has better claims on us you think/Than on his brother? . . . /Why didn't he go there? His brother's rich./A somebody—a director in the bank."

While many families have not abandoned a relative with AIDS, irrational fear of transmission added to religious or cultural stigma have led to rejection. Even among Jewish families, often stereotyped as the most protective and supportive of their children, AIDS creates divisions. In 1989, eight years into the HIV epidemic, a New York City congregation held a special, separate Passover seder for its members with AIDS because some of their families were afraid to invite them to the family gathering and risk the wrath of those who wanted no association with AIDS (*Newsday* 1989a).

Because nontraditional families are more commonly socially and psychologically similar to the patient, having been deliberately formed

around shared interests, they may be better equipped to respond to external pressures such as stigma, but not to the dependency and level of care occasioned by illness. Most of these family members are young; caring for someone their own age who is dying may be particularly traumatic. Where a number of people are involved, competition for the ill person's reliance and trust may erupt. Susan Sontag's (1986) short story, "The Way We Live Now," depicts such a web of complex interrelationships:

According to Lewis, he talked more often about those who visited more often, which is natural, said Betsy, I think he's even keeping a tally. And among those who came or checked in by phone every day, the inner circle as it were, those who were getting more points, there was still a further competition, which was what was getting on Betsy's nerves, she confessed to Jan; there's always that vulgar jockeying for position around the bedside of the gravely ill.

In some cases only certain family members are involved in the care and support of the person with AIDS; in others, the roles and functions are shared and rearranged to meet the needs of the moment. In still others, families are in conflict, occasionally or permanently, over issues such as treatment decisions, disposition of property, and funeral arrangements. Within all families, relationships may shift over time, as individuals move in and out of different roles and functions.

Nontraditional Families and Social Institutions: Slouching toward Flexibility

While some families have demonstrated remarkable capacities to adjust to the stress of AIDS, the institutions that serve as their formal social support—the law, welfare systems, health care, insurance, housing—are less flexible. AIDS is only one of many situations revealing the inadequacies of these institutions in responding to the needs of non-traditional families, but because of its high visibility and urgency, it could be a catalyst for change.

American social institutions were constructed with a particular vision of the family that was a dim reflection of the reality of many minority, immigrant, poor, or other families out of the white middle-class mainstream. These institutions are ill prepared to deal with the complex,

novel, and highly charged issues presented by AIDS. Their inadequacy is apparent at many points between diagnosis of AIDS and death and even beyond. Courts and other agencies have, however, already had to confront the problem in three areas: (1) decisions about medical treatment; (2) housing; and (3) custody decisions.

Decisions about Medical Treatment

A central focus of the field of biomedical ethics, which began in the 1960s as a response to the biological revolution and the prevailing norm of medical paternalism, has been patient autonomy—the right of competent individuals to make health care decisions for themselves. When the person is unable to make those decisions, either because of illness or legal incompetence, the classic question has been: “Who decides?”

Legal efforts to ensure the rights of individuals to make treatment decisions or to designate a particular person as a proxy have centered on some form of advance directive or “living will.” These documents set out the patient’s wishes concerning what kinds of treatment are acceptable and under what conditions, and they may designate a person to act as proxy. Thirty-eight states and the District of Columbia now recognize advance directives for treatment decisions (Society for the Right to Die 1987). Eighteen states have legalized the patient’s appointment of a durable power of attorney in health care to express the patient’s wishes if the patient becomes incompetent (Cohen 1987). While durable powers of attorney are well established in financial matters, their status in health care is less certain, and decisions made by a person designated in this capacity may be challenged.

Although not legally entitled to make treatment decisions, “the family” has generally been considered the appropriate surrogate. In the hierarchy of decision makers, parents are normally considered surrogates for minor children, spouses take on the surrogate role after marriage, and children act as surrogates for widowed, elderly parents. When the family structure does not conform to these patterns, or is not defined by traditional relationships, conflicts among family members, and between family members and physicians or hospitals, may arise. Controversies concerning termination of life supports have been at the center of biomedical ethics discourse.

Bringing a new set of actors—lovers and nontraditional family members—into the equation complicates the decision-making process and sets the stage for conflict. A Minnesota case involving two lesbians has become a symbol for advocates of the rights of women, gay people, and the disabled. Sharon Kowalski, a former high-school physical-education teacher, became paralyzed and suffered brain damage after an automobile accident in November 1983. After the accident the woman with whom she had lived, Karen Thompson, told Ms. Kowalski's parents about their lesbian relationship. Mr. Kowalski was named his daughter's guardian in an out-of-court agreement that allowed Ms. Thompson broad visiting rights to Ms. Kowalski, who was in a nursing home. In July 1985 Mr. Kowalski received unconditional guardianship and barred Ms. Thompson and other friends from any contact with his daughter. In September 1988, Ms. Kowalski was moved, by a court order, to a different nursing home for an evaluation of her competency, and there she was reunited with Ms. Thompson. The final determination of her competency, placement, and guardianship are still unsettled (*New York Times* 1989a).

Similar cases arise when one partner has AIDS. When the disease involves neurological impairments and dementia as an end-stage complication, the issue of a patient's competence is further clouded. Molly Cooke, a physician at San Francisco General Hospital, describes a typical case. A 27-year-old man with AIDS designated his lover as proxy and stated clearly that he did not want "heroics" when he reached the terminal stage of his illness. The physician understood him to mean that he refused intubation and mechanical ventilation. When the patient's parents arrived to visit him from out of town, they learned that he was gay at the same time that they learned he had AIDS. Angry and upset, they insisted that "everything be done" and threatened to sue the hospital. The lover withdrew as proxy and the physicians felt obliged to continue aggressive treatment. The patient died after 22 days on a respirator in the intensive care unit (Cooke 1986).

In another San Francisco case, a 32-year-old gay man with Kaposi's sarcoma had been abandoned as a child by his parents and was raised by a grandmother. She refused to care for him when she learned of his diagnosis. His siblings refused to visit him, and his parents wrote to tell him that God was punishing him for being gay. The patient designated his partner as his durable power of attorney for health care, and affirmed his refusal of intubation should he become incompetent. Af-

ter his death, the patient's father insisted that the body be flown to the Midwest for burial, even though the patient had stated his desire for cremation and a local funeral. In this case the patient's wishes were honored, because of the durable power of attorney (Steinbrook et al. 1985).

In still another case which reached the courts, Thomas Wirth, an AIDS patient at Bellevue Hospital in New York City, signed a living will refusing extraordinary treatment and naming a friend, John Evans, as guardian. The physicians challenged the directive, however, because it did not clearly specify which treatments were being refused. Evans took the case to court, but the court upheld the physicians. They argued that the particular condition that they were proposing to treat—a brain infection—was not by itself fatal. Mr. Wirth died soon after the decision.¹

These cases illustrate common dilemmas but they are atypical in one respect: In each case the patient had clear preferences and had taken some steps to implement them. Unfortunately, as Cooke (1986, 345) points out, "many patients will be admitted to the hospital unable to express their wishes, without a previous documented discussion and without having appointed a proxy with durable power of attorney." If this is true among the predominately gay patient population of San Francisco, it is even more the case among the drug users and their sexual partners who now make up the majority of cases in New York City.

Kevin Kelly (1987), a psychiatrist at New York Hospital, has raised another possibility:

Until now, the prevailing practice has been that, when a decision cannot be made by the patient or responsible others, physicians feel obliged to proceed as if the patient had given consent for all possible measures, but this epidemic may force us to reconsider this practice, and to substitute an alternative model in which the patient is assumed to have withheld consent unless it is specifically given.

Acknowledging that this model would sharply conflict with legal precedent, Kelly suggests that it would be applicable only when the patient is known to have an irreversibly terminal illness, his or her wishes cannot be determined, and there is no one else to make the decision. Such a model may hold considerable appeal for physicians, especially since

¹*Evans v. Bellevue Hospital*, (re Wirth), 16536 N.Y. Sup. (July 27, 1987).

some of the life-prolonging interventions, which are generally futile anyway, involve an additional, albeit small level of risk of HIV exposure to health care workers through needle sticks and blood splashes. It would, however, result in withholding care from a particular class of patients on the basis of their social status. The category of patients most likely to be affected would be the poor, probably minority, drug user, isolated from both family and friends. These patients would also be more likely to enter the health care system at a later stage of disease, thereby being more likely to have diminished competence. To deny care to such patients when care would be provided to similar patients who were fortunate enough to have social supports would be discriminatory.

Thus, AIDS is having an impact on treatment decisions. Physicians who regularly care for gay AIDS patients, as well as many patients themselves, are moving toward early, specific, and ongoing discussions about treatment, including its termination. The *AIDS Legal Guide* encourages persons with AIDS to "sign a Living Will if it represents their sentiments on the matter, because it serves as a communication of one's intent at a later time when one is no longer able to communicate" (Rubenfeld 1987, sec.9, p.4). The New York State law on "orders not to resuscitate," passed in April 1988, specifically included "a close friend" among those who may be designated to act as surrogate on behalf of the patient to acknowledge the rights of gay partners to participate in "do not resuscitate" (DNR) decisions² (Nancy Dubler, personal communication 1988). This trend clearly strengthens the force of advance directives in non-AIDS cases and sets an example for physician/patient communication for other life-threatening illnesses.

But autonomous decision making in matters of health care may be neither as important nor as easy to implement for patients from poor, minority backgrounds. A sense of fatalism, powerlessness, religious traditions, acquiescence to the wishes of others—whether they are family or physicians—all may work against patient self-determination. Intravenous drug users are not generally interested in talking about living wills and durable powers of attorney; they just want to be treated, hoping and praying for the best. Here too, AIDS will test boundaries, in this case those of personal autonomy and family control.

²New York State Public Health Law, Article 29-B (Orders not to resuscitate), L. 1987, ch. 818. Effective April 1, 1988.

AIDS may change the boundaries to include serious considerations of euthanasia or "assisted suicide," thus creating an enormous additional potential for conflict within families. AIDS may even test the validity of informed consent as the basis of medical decision making. At the very least it will require renewed attention to the importance of communication among and between patient, physician, and family. Physicians and hospital ethics committees may need special help in understanding, accepting, and dealing with nontraditional family members as participants in this process. When the appointed surrogate—for information or for decision making—does not bear the usual relationship to the patient, traditional norms of professional practice may be threatened.

Housing

All families need shelter, and nontraditional families have particular difficulties in obtaining and retaining housing, because of restrictive zoning ordinances and tenancy laws. Zoning laws established in the post-World-War-II building boom reflected the expectation that the typical family would consist of parents and children. Furthermore, zoning ordinances were intended to protect property values; deviations from the norm of the traditional family constellation are seen as economic threats. Such ordinances typically prohibit nonrelated individuals from sharing a single-family home. Thus, in addition to gay couples or young unmarried heterosexual couples, elderly couples who cannot afford to marry because their Social Security payments will be reduced may have difficulty in finding a place to live.

In Denver in May 1989, after considerable discussion, the city council voted to amend its 36-year-old ordinance and allow two adults unrelated by blood, marriage, or adoption to live in the same house. The new ordinance also eliminates a \$20 room-and-board permit for an unrelated couple living together. The earlier prohibition affected mainly unmarried couples living together, as well as single parents who rent out rooms to tenants to help defray expenses (*New York Times* 1989f, 1989g). Councilwoman Mary de Groot applauded the ruling: "Zoning should be used for regulating land use and density, not relationships." An opponent of the change, Councilman Bill Roberts, who is black, saw the move, however, as threatening Afro-American family stability:

“The most stable environment in which to raise children is in a house with a mother and a father who have a commitment to each other.”

New York’s highest court, the State Court of Appeals, upheld a lower court that ruled that the town of Brookhaven’s zoning law violated the state constitution by restricting the number of unrelated people who could live together as a “functionally equivalent family.” The decision will make it easier for unrelated individuals to live together in areas previously restricted to single-family use (*New York Times* 1989e).

In 1974 the U.S. Supreme Court had, however, upheld a law in the village of Belle Terre, also in Long Island, that defined a family as people related by blood, marriage, or adoption, or not more than two unrelated people. Recent amendments to the Federal Fair Housing Act, extending governmental protections against housing discrimination to disabled people and families with children, may have a powerful impact on the rights of people with AIDS and their families to obtain housing (*New York Times* 1989d).

In urban areas, a common problem arises when the person named on a lease dies and the surviving partner or family member claims the right to remain as a tenant in a rent-controlled or rent-stabilized apartment. The case of *Braschi v. Stahl Associates Company*³ in New York City is the most significant legal challenge to the practice of limiting survivors’ rights to traditional family members. Although the case involves a gay couple, the precedent it sets will be important for many people affected by the disease in low-income, minority communities, as well as for unmarried heterosexual couples and other nontraditional families. The situation is particularly dire for survivors who themselves are HIV-infected or have AIDS or who have responsibility for caring for another family member with AIDS. Eviction from an apartment upon the death of the primary tenant can lead to homelessness for the survivors.

Miguel Braschi lived with his life-partner Leslie Blanchard in Blanchard’s rent-controlled New York City apartment for ten years, until Blanchard died of AIDS. Braschi, who was Blanchard’s primary caregiver throughout his illness, was informed by the landlord that he was being evicted. The Supreme Court of New York County granted a preliminary injunction, halting the eviction. The judge found that, on the

³*Braschi v. Stahl Associates Company*, 74 N.Y. 2d 201 (1989).

basis of the ten-year relationship, Braschi was a "family member" within the meaning of the rent control law, Section 56(d) of the New York City Rent, Rehabilitation and Eviction Regulations. This section provides that "family members who reside continuously for at least six months with the tenant of record, continue as rent-controlled tenants even after the tenant of record dies or vacates the premises."

The landlord appealed, and the appellate division unanimously reversed the decision. While it recognized that Braschi had proved that the relationship with the tenant had been "marked by love and fidelity for each other," it interpreted the rent control law "as only protecting surviving spouses and family members within traditional, legally recognized familial relationships." Braschi received permission for a direct appeal to the Court of Appeals, which decided in his favor in July 1989. Writing for the majority, Judge Titone said: "The term family . . . should not be rigidly restricted to those people who have formalized their relationship by obtaining, for instance, a marriage certificate or an adoption order. The intended protection against sudden eviction should not rest on fictitious legal distinctions or genetic history, but instead should find its foundation in the reality of family life." Further cases will undoubtedly seek to extend the ruling to rent-stabilized apartments and other types of housing, and some difficulties can also be expected in defining whether a particular couple meet the criteria for "family" set out in the decision—"two adult lifetime partners whose relationship is long-term and characterized by an emotional and financial commitment and interdependence."

Custody Decisions

Parents are normally responsible for the care and nurturing of their children. But when circumstances prevent one or both parents from fulfilling this obligation, courts determine who shall have custody of the child. The state's interest is in seeing that the child is protected, as much as possible, from the harmful effects of divorce, separation, or death. Traditionally, judges have wide latitude in determining a child's "best interests." Until recently the traditional presumption has favored, however, the biological mother. The *Baby M* case in New Jersey marked a deviation from this traditional course; the biological or "surrogate" mother, Mary Beth Whitehead, was defeated in her bid for

custody by the biological father William Stern and the adoptive mother Elizabeth Stern. In general, courts are becoming much more responsive to paternal claims for custody.

Against this background, conflicts about custody of children related to AIDS or HIV infection arise in two broad contexts: visitation rights in separation and divorce cases, where one parent is lesbian or gay or is HIV-infected or has AIDS; and the placement of children following the death of a parent with AIDS.

As homosexuality has become more openly discussed and, arguably, more accepted in society, homosexual or bisexual parents have become more willing to seek custody of their children when a marriage or sexual relationship dissolves. And in general more courts have been willing to accept these nontraditional relationships. But to the already volatile atmosphere of a failed relationship, the question of HIV infection adds an explosive charge.

How will judges weigh HIV status in making custody decisions? A judge who might have been willing to grant custody to a gay parent may not be so amenable if he is misinformed about the possibilities of HIV transmission in a family setting. In the Indiana case of *Stewart v. Stewart*,⁴ Mr. Stewart sought to regain visitation rights to his one-year-old daughter after his former wife refused to let him see her. Mrs. Stewart was addicted to drugs and alcohol, and had lost custody of her first two children before she met and married Mr. Stewart. A trial court held that Mr. Stewart could be denied all visitation rights to his daughter because he was HIV positive, although asymptomatic. An appeals court ruled, however, that HIV infection per se was not a reason to deny custody or visitation.

A New York court ruled, in *Jane and John Doe v. Richard Roe*,⁵ that a father who had custody of his two children did not have to undergo HIV antibody testing as a condition of retaining custody, as the children's maternal grandparents had requested. The court in *Ann D. v. Raymond D.*⁶ made a similar finding, ruling that "a positive test result may not automatically be a 'determinant factor' with respect to plaintiff's ability to be a custodial parent."

Courts in other jurisdictions, however, have restricted the visitation

⁴*Stewart v. Stewart*, 521 N.E. 2d 956 (Ind. Ct. App. 1988).

⁵*Jane and John Doe v. Richard Roe*, 526 N.Y. Sup. 718 (March 14, 1988).

⁶*Ann D. v. Raymond D.*, 528 N.Y. 2d 718 (1988).

rights of a parent with AIDS. For example, a New Jersey court ordered that a father with AIDS could not visit his child without supervision.⁷

Based on a review of the scientific and legal literature, Nancy Mahon (1988) concludes:

A court's use of a parent's HIV infection as per se evidence of parental unfitness contravenes the best interests standard . . . unless judges perform a factually specific examination of how a particular parent's HIV infection affects a child, the child's best interests cannot be served.

Will future courts follow this standard? It will depend on judges' level of understanding and education. Hard cases, however, will inevitably arise, in which a parent's desire for custody must be weighed against the ability of that parent to provide appropriate care if he or she is seriously ill and likely to die or engaging in behavior like drug use that undermines the stability of the child's life.

A second category of custody case is arising as increasing numbers of mothers become ill with AIDS. These cases now occur where there are substantial numbers of infected and ill women, especially in New York, New Jersey, and Florida; as the epidemic progresses, they may be expected to arise elsewhere. The New York City Task Force estimates that "over the next few years a minimum of 60,000–70,000 children in New York City will lose at least one parent to AIDS. Of these, maybe 10,000 will lose both parents to the disease" (New York City AIDS Task Force 1988).

The surviving children, some of whom may be HIV-infected but many of whom are not, must be placed in someone's care. Whose should it be? The options for these children, the majority of them from poor minority families, are few and frequently bleak: placement with a member of the extended family who may be beset by the same social and economic problems as the natural mother; foster care, with its inherent impermanence; adoption, which is unlikely to be available for older children.

Frequently, decisions about custody are made by a dying mother; her wishes may conflict with those of surviving family members, the child, or the professional team caring for her. Sometimes a child may

⁷*Jordan v. Jordan*, FV 12-1357-84 (Middlesex County, N.J., Sup.).

wish to live with a relative whom the professionals consider ill-equipped for the responsibility but who may be the only biological relative. The legal options available to confer guardianship, such as testamentary provisions or deeds, are fraught with uncertainties (C. Zuckerman, personal communication 1988).

As family courts become overwhelmed with these cases (not just as a result of AIDS, but of drug, particularly crack, addiction as well), it is likely that the decisions will be based more on which party has the most effective legal representation and not on the ill-defined concept of "best interests of the child." In addition to effective representation for mothers, advocates for the children may be required to ensure that they do not become pawns in an intra- or interfamilial or agency/family dispute.

It is possible that courts' traditional preference for granting custody to biological parents, even those who have not demonstrated a high level of concern for their children, may collapse under the weight of the caseload of orphaned children and drug-addicted parents. The foster care systems in affected communities may also be unable to accommodate a huge number of children with multiple problems, because many of the potential foster parents may also be affected by the disease. If the foster care system collapses, it is possible that some children may be placed in states far from their communities of origin, rather like the Asian children brought to this country by adoptive parents. It is also possible that the very foundation of child placement since the Progressive Era—that children are better off in families than in institutions—may be re-examined. In New York City, however, group homes set up to accommodate "boarder babies" released from hospitals and awaiting foster care placement are understaffed, in disrepair, and violate health and safety regulations (*New York Times* 1989h).

In the future, custody decisions may, from necessity as much as principle, accommodate a wide variety of nontraditional family placements. With increased flexibility in these arrangements, it seems likely that most children could be placed in families. But some children—those hardest to place or those living in areas where families able and willing to accept them are in short supply—may have to live in institutions. Lois Forer (1988), a retired family court judge in Philadelphia who has seen at first hand the failures of both families and foster care, has already called for a return of orphanages. She says:

Public institutions are answerable to the public. They can be inspected regularly by public officials. Committees of private citizens can act as overseers and keep a careful eye on the operations of such orphanages. It is difficult and expensive for social workers to inspect at frequent intervals all foster homes.

The choice may come down to admittedly inadequate family placement and admittedly but differently inadequate institutional placement. A change in basic social work philosophy, which has favored families over institutions, would be profound and disturbing, but is not unthinkable.

The Formation of New Families

The process of change and adaptation is incomplete. Just as existing families continue to adjust to the exigencies of AIDS, the formation of new families may also be affected by law and changing custom. Individuals do not ordinarily make the commitment that defines "family" without considerable prior interaction with the potential partner. Families start out as relationships. If evidence for the impact of AIDS in the areas already described is scant, it is even more fragmentary the more one looks to the future for families. This final section is, therefore, largely speculative.

Some changes may reflect the epidemiology of AIDS. For example, in some minority communities, large numbers of men and women of childbearing age are HIV-infected. These communities place a high cultural value on reproduction; children are seen as proof of virility or femininity, sources of pleasure, links to the past, and hope for the future. How will HIV infection, and the consequent threat of the birth of HIV-infected babies, affect the formation of new relationships in these communities? Will a partner's HIV status be an important determinant? Will the post-AIDS society envisioned in Margaret Atwood's (1986) *The Handmaid's Tale*, in which healthy women serve as breeders, come to pass? It is not implausible that the wives of hemophiliacs or other men with HIV infection will choose artificial insemination rather than risk unprotected sex, HIV transmission to themselves, and infection of their fetuses. Nor is it far-fetched to think that some infected women would choose not to bear children themselves but would engage a surrogate for that purpose.

Even among groups where procreation is not a supreme value, HIV status may be influential in the formation of new relationships that might lead to procreation. Public policy and medical practice may play a significant role. The intent of mandatory premarital HIV screening (which was tried and abandoned in Louisiana and later in Illinois), as well as of less coercive efforts to encourage voluntary testing among couples about to be married or women considering pregnancy, is to discourage marriage and reproduction among HIV-infected partners. For example, two epidemiologists reviewing data about heterosexual transmission concluded that "societies may soon have to wrestle with many difficult questions, including the suitability of infected individuals for marriage and natural parenthood" (Haverkos and Edelman 1988). In challenging this "incautiously worded" comment, Ronald Bayer (1989) declared: "Both moral sensibilities and our constitutional tradition revolt at the notion that classes of adults—defined in terms of biologic factors—be barred from marriage." The authors replied: "We personally do not support criminalized marriage, criminalized childbirth, coerced abortion, or compulsory sterilization. . . . Nevertheless, . . . we can predict that as the pandemic widens and deepens in our society, increasingly powerful voices will be heard calling for such state-imposed restrictions" (Edelman and Haverkos 1989).

So far only one state (Utah) has passed a law invalidating marriages involving an HIV-infected partner. This law has not been tested. While the intent of the Utah law may be to protect traditional family norms, another source of opposition to sex involving HIV-infected partners comes from the Rajneesh religious communities, which reject exclusive, monogamous relationships. In their view, AIDS confirms their belief that AIDS is the result of sexual repression. One Rajneeshee explained: "What they [all those Christians and bourgeoisie] can't see is that the family is what drove all those people to rebel in the first place—to become homosexuals and junkies. So, returning to the family would only worsen the situation!" (Palmer 1989).

While organized opposition to marriage or sex involving an infected person may be limited, personal choices of sexual and especially marriage partners, only recently (and incompletely) freed from considerations of religion, race, and economic or social status, may be tempered by disease. Even though AIDS is becoming a chronic illness, the HIV-infected person has a shorter life span than a healthy person. Those involved in a sexual relationship, which includes the vast majority of

married couples, must always be constrained by concerns about transmission. An attorney with hemophilia described a failed romance:

Not long after I was diagnosed as carrying the virus, I began dating a bright, attractive woman. I wanted to kiss her—certainly no big thing under normal circumstances. But I felt I must first tell her about the virus. . . . On a rational basis, she grasped that kissing me would almost certainly not be dangerous. But AIDS has taken on an identity all its own. . . . It was a world of which she wanted no part. Recreational sex was not worth risking one's life for, she explained, and what was the point of developing strong emotions for someone who could not lead a normal sex and family life? (*New York Times Magazine* 1989a).

Disagreeing that life with HIV infection was inevitably asexual, the wife of a hemophiliac who died of AIDS nevertheless responded in a way that seemed to bear out the attorney's fears:

I married my husband . . . after he was diagnosed with AIDS. It is true that we had a pre-existing relationship. However, it is also true that we had a romantic and sexual life after he was diagnosed. . . . I admit that the latter made me and my husband anxious, and that the anxiety could not be overcome completely (*New York Times Magazine* 1989b).

Although the stigma and discrimination surrounding the disease may diminish, they will not disappear. While existing relationships may survive and even be strengthened by knowledge of a partner's HIV infection, the formation of new relationships may well be deterred by the realities of the situation. On the other hand, there may be greater interest in, and social acceptance of, the legalization of marriages between homosexual partners (*New York Times* 1989c). The City of San Francisco's registry of "domestic partners" is a step toward legalization. Even in the absence of a formal mechanism, gay couples may announce their commitment in other ways. In New York City, Michael Feuerstein, who works on AIDS programs in the Department of Health, and his lover, Luke Denobriga, a hairdresser, announced their plans to hold a "commitment ceremony" and to change their name to Mr. and Mr. Stanton (Luke's actual first name). In a memo to his colleagues, Mr. Feuerstein said:

There is no mechanism in our society for gay people to publicly announce their relationships or "marriage." We're not permitted, by law, to marry. A recent trend in the Gay and Lesbian Community has been toward commitment ceremonies, wedding-like events for family and friends similar to those heterosexual people have been enjoying for centuries" (*Newsday* 1989b).

In this explication the differences between nontraditional and traditional families seem less important than their similarities. AIDS is both heightening the creation of nontraditional families and presenting special problems for them. AIDS threatens the intimacy and acceptance that ideally undergird family relationships, while at the same time making them all the more powerful and necessary.

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