

Needed (For Women and Children)

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Needed (For Women and Children):

SUKI PORTS

AIDS is the major killer of women between the ages of twenty-five and thirty-four in New York City. In December of 1985, there were 487 women and 103 babies with AIDS. The majority were black, Hispanic, Asian, Native American, and "unknown other." Exactly two years later, in December 1987, the numbers in New York had risen to 1,364 women with AIDS and 231 pediatric cases—with the majority again being disproportionately from minority communities. AIDS occurs mainly among the poor, whose opportunities for obtaining comprehensive services during pregnancy or illness, at death, and for survivor children are slight. Appropriate housing, family case management, child care, and mental health support systems are even more limited, and AIDS has only exacerbated this situation.

Women are normally the care givers for the ill, so when they themselves become ill, who will care for them? There is no inclusive coordinated care system in place for them. We must not continue the patchwork, band-aid approach to AIDS care for women. Comprehensive extended support systems must be developed for families—whether traditional nuclear families, extended families, single sex couples and lovers with children, or the growing numbers of single parent families.

The fastest growing numbers of AIDS cases are among women, and, again, this means primarily minority women (eighty-four percent in New York City). While black and Hispanic women are disproportionately and increasingly affected by AIDS, the media insensitively and incorrectly tells us that the heterosexual spread of AIDS is not really a threat. How does a black or Hispanic woman feel when she hears this? Prostitutes, of course, continue to receive headlines, but only to be scapegoated as "vectors" of the disease, even though female-to-male transmission is considerably less common (or documented) than male-to-female transmission. Women have not achieved full equality in the job market, let alone in bed, and yet condom ads continue to place the necessity of protected sex on women.

While women have displayed incredible stamina, courage, and resourcefulness, AIDS has played a cruel trick upon their coping skills. Their strength is

sapped caring for children, preparing meals, cleaning, shopping, and doing laundry—leaving little energy for personal care or the mother's additional duties of relating to schools, taking her children to the park or on special outings. Exhaustion is compounded by a sense of isolation. Among the factors that contribute to this additional impact of AIDS upon women are fear of eviction if neighbors find out that they or their children have AIDS, loss of support if the extended family finds out, loss of a lover or husband, "coping" if drugs are in any way involved, dismissal of their children from school if other parents or school board members find out. The low-income mother faced—alone—with these seemingly never-ending problems does not have recourse to, say, insurance-paid psychiatric counseling—a need that is of primary importance for anyone faced with HIV infection, both at the time of diagnosis and during the extended process of explaining such information to children, family, or friends.

Counseling, as an aid to coping and healing for those affected by AIDS, is generally frustrated by the limited availability of personnel who can relate to specific ethnic, racial, class, or language needs. The counselor must be able to deal effectively and with compassion with a broad range of psychosocial concerns, often including confronting a drug problem in whatever way it might be manifested. For adults, there is the need to face death and to make practical as well as emotional decisions about children. For children in a family affected by AIDS there are equally powerful and emotionally complex issues. One young nine-year-old recently stated, "When Mommy dies, it will be my fault." No counselor of the same ethnic background was immediately willing to visit the home of this young boy. AIDS often means that young people must come to an understanding of the illness and/or death of the person closest to them. It also means that they must comprehend why certain other parents might forbid their children to play with them, or why even a family member might shun them. And it means they have to face the fears they have now and, more frighteningly, an ultimate grief upon the death of a loved one, which they might have to bear alone or with little immediate or sustained empathy.

NEEDED: An appropriate means of dealing with death in a family, tailored to the needs of individual children of different ages. If we do not train people now, we will face—unprepared—thousands of children left behind by the deaths of their mothers, fathers, or both. This loss, this legacy of children left behind and unable to cope with their grief, will precipitate a crisis that we have yet to tackle in any nationwide or community-specific manner. We have an entire generation of physically well (or possibly potentially ill) children to plan for and protect.

—Originally diagnosed and hospitalized with tuberculosis, Jane, the grandmother of a three-year-old boy, was soon diagnosed with AIDS. Because there was no nursing home willing to care for her, she lived the next seven—and final—months of her life in a major urban hospital. Already overburdened with

an average daily caseload of forty-five people with AIDS or other HIV-related illnesses, the hospital's infectious disease, psychiatric, and social support personnel interpreted Jane's early signs of AIDS-related dementia as nothing other than a grandmother's senility or lack of cooperativeness. Generally on alternate-level (as opposed to acute) care, Jane was resented by a staff forced to attend to her when they knew that what she really needed was a nursing care facility. Jane, in turn, resented their lack of attention. At some point during her hospitalization, her lower plate was lost, and its replacement was not a high priority on anyone's list but Jane's. Her once dry sense of humor and winsome smile contrasted sharply with the erratic and uncooperative behavior of this often cranky and complaining woman, whose facial appearance had now changed as much as her temperament. On one of my visits to another patient in her room I discovered that Jane and I were "twins"—sharing the same birth date and year. We compared stories of our "grands," and she always spoke of her sadness at missing out on seeing her grandson grow up. The little boy finally did see his grandmother . . . he was all dressed up in a gray suit and matching tie, shiny black shoes, and a look of puzzlement as he was walked past her open coffin.

NEEDED: A change in funding streams, which will provide, from the federal to the city level, housing for indigent seniors, including and especially those with AIDS. A little far-sightedness will ultimately result in fiscal soundness. The needs of senior citizens are the same as those of PWAs—ramps, handrails, elevators, doors with wheelchair and/or stretcher access, and spaces for group social activities including meals, family meetings, outpatient medical care, and private counseling. The housing required by both groups could be built into any rehabilitation of abandoned structures. Per diem costs would be far less than the toll now paid in actual dollars and in the demoralization of personnel, to say nothing of that of clients.

NEEDED: The funding necessary to enable care givers to get special training that would not only provide them with the most accurate and updated AIDS information to help them respond to PWAs' myriad questions, but take into account the extraordinary stress and strain of such a health care service by building-in adequate internal support and respite systems for all workers. AIDS care must not be static, lacking in compassion, or inadequate because of ignorance or overwork.

NEEDED: The ability to provide other than acute medical care for low-income PWAs, i.e., dental care, mental health counseling, and planning for legal and other business needs for both PWAs and their families.

NEEDED: Additional auxiliary personnel who have the time to consider and plan for the fulfillment of human needs. Jane, whose long life ended separated

from family, and with the added indignity of not being able to eat well due to the lack of lower teeth, is but one painful example of an overburdened system's turning its back on the needs of individuals. Low-income communities cannot produce the same numbers of volunteers ("candy strippers") as the more affluent communities, which have both public and private hospitals within their boundaries.

—Mary was a tall, statuesque, thirty-one-year-old woman who became weak and thin almost before your eyes. Oral thrush made it difficult for her to talk and, consequently, difficult for her boyfriend to communicate with her. He eventually became discouraged by this, as well as by Mary's countless trips to the hospital's inpatient and outpatient clinics, and so he left her—which, needless to say, sent Mary into a deep depression. Only the stern intervention of a very caring infectious disease physician made the boyfriend see the vital role he played in both her physical and emotional health.

NEEDED: Time and funds for additional trained staff to participate in the education of family members—including lovers—and neighbors of PWAs. Where appropriate, family reconciliation needs to be nurtured.

—Betty, who had a teenage daughter, acted like a spoiled, manipulative adolescent herself. She frequently suffered from boredom, which caused her moods to swing dramatically from those of a crying, wily childlike person, who begged for cigarettes and specific candy or food, to a completely uncooperative patient whose abusive behavior was directed primarily at the overburdened nursing staff.

NEEDED: The availability of a TV in a social setting. This space might also serve as a place where some vocational or other training classes (i.e., writing skills or crafts) might be taught. Such an allotted space within an institution would allow patients who are sometimes in the hospital for long periods of time the opportunity to occupy themselves, while also providing them with valuable information that we mistakenly assume they get by osmosis. It could be the location for the dissemination of reading materials and information about AIDS, ranging from general home precautionary guidelines to practical nutrition recommendations. Nutrition information cannot be taken for granted within poor communities. AIDS care is completely out of step with the needs of people who must make their purchases on food stamps or whose ethnically oriented local grocery stores limit the availability of certain foods.

—Rosa, with five children from ages two to twenty, struggled with her religious upbringing and country of origin's traditions and finally decided it would be most responsible if she aborted her sixth child and had her tubes tied.

She did not count on the fact that this very difficult personal decision would be met by a three-week delay due to fear and unwillingness to deal with an HIV-infected woman on the part of a surgeon, a lab technician, and a nurse. After going through the humiliation of rejection by one medical staff person after another, she finally was scheduled for an overnight stay. We asked the appropriate city agency that child care be provided by a caretaker who was familiar to the children and who was willing to spend the night, although existing norms place children in temporary foster care. During the surgical procedure Rosa's uterus was perforated, thus requiring that a total hysterectomy be performed. She remained in pain many hours after returning to her room because no one had written orders for medication for this procedure. Given the lack of attention to Rosa's immediate health needs, it should come as no surprise that no one authorized the extension of the child care for the entire week now required for her hospitalization.

NEEDED: Coordination and sharing of information and training of all hospital personnel, particularly those who might come into contact with AIDS-related problems, and not only those in infectious disease units. Social services must be sufficiently organized and coordinated with medical personnel so that, for example, the infectious disease staff can alert general surgery (or others) when a particular patient might be hospitalized for a reason other than AIDS.

NEEDED: Child and family care based upon a Family Case Management system responsive to the needs of any member of a family in which there is a person with AIDS or HIV infection. This seemingly simple and commonsense need is not met because of existing rules for reimbursement, job definition, union work regulations, and scope of training. A major overhaul of child care and home care is long overdue, but AIDS-related needs have created a new crisis, and the gaps are glaring, as are the ramifications for affected families. In many cases the lowest-paid women are asked to provide the most support for difficult situations—without provisions for their own health, vacation, and other benefits.

—A mother with an income in the low twenty-thousand-dollar range has to quit work to take care of her child, who is HIV positive, because her income is too high to be eligible for free child care and too low to pay the going rates for private care. She cannot put her daughter in day care, as the child must be taken to a clinic weekly for medication and checkups. The mother's welfare payments do not cover her rent increase, the extra carfares needed to go to and from the hospital, extra pampers and special foods required by the child so as to avoid effects of diarrhea. As if it were not enough that this woman, who has never been on welfare, must face the emotional stress of a change in financial status and the painful realities of a child sick with a life-threatening disease (which might

engender feelings of guilt and inadequacy on her part), she must also deal with the possibility of losing her home.

—Another mother is single and weak with AIDS. She qualifies for home care, but her children, who are healthy, might be sent to foster care because the adult-care worker is reporting that the mother neglects her children. Existing regulations do not require or even permit the home attendant assigned to an adult to feed the children the same food prepared for the mother. A duplication of workers is provided only after further reports of “neglect.” This loving mother, who wishes to keep her family intact as long as possible, is faced with the “choice” of sending them to foster care or having neglect charges filed against her. The final result was that her children were placed in the home of strangers.

NEEDED: The development of a new definition of AIDS family care givers, with special training in AIDS care for any and all members of a “family.” Perhaps the Peace Corps could serve as a model for a program that would draw people from a variety of backgrounds, including mothers whose children have grown up and left the nest, recent graduates with related academic interests who are undecided in career choice; these people might also include women who had been incarcerated and had received a special training certificate while institutionalized, or women on welfare who would be allowed to augment payments or who could get off welfare entirely, having been trained with skills for a new family health care career.

The foregoing examples of women who have experienced a multitude of problems with the onset of AIDS or HIV infection—either their own or that of a member of their family—represent but a glimpse of the multi-dimensional effects of AIDS upon women. But of what women are we speaking? For the most part, women who have lived difficult lives already: women who are (or were) drug users or who have been sexually involved with a drug user. They are also women who generally have low incomes, who have had little opportunity for higher education, and who have limited job opportunities. In the United States they are, for the most part, black and Hispanic. As a group of women at the Third International Conference on AIDS in June of 1987 stated, “AIDS offers a paradigm for all of the critical issues which impact upon women” (see pp. 166–168).

—A young black mother recently stated, with tears in her eyes, gripping the hand of her husband, “If it was not for Robert’s support and being there, I would have committed suicide. When my baby was born she was beautiful. Now my baby is dying of AIDS.”

—Lisette, when well enough to be ambulatory, helps older patients eat,

combs their hair, acts as a nurse's aide and personal care giver, and is generally an outgoing spirit-picker-upper. But she has recently been depressed. She worries about her baby (age three) who is now seropositive, and her only healthy child (an adolescent), who just had an abortion. Lisette lost her husband, middle child, and a stepsister to AIDS. She has tried to commit suicide. Abused as a young girl, Lisette escaped from the world of school into a world of sex and drugs and became pregnant at sixteen. She cautions young women, "Learn more about life and yourself before trying to raise a family."

But we must ask: What are responsible adults doing to ensure that adolescents are getting specific AIDS prevention information? What is the prevailing knowledge among teenagers? What precautions are they taking?

In the December 1987 issue of *New Youth Connections, NYC*, the results of a survey from the previous month were printed in an article entitled "Thinking about AIDS." It is a sobering look at what teens believe in the city with the highest case incidence of AIDS in the world:

— Thirty-three percent think that you can only get AIDS by having sexual relations with a gay man.

— Sixty-eight percent of the sexually active readers who responded either never or only sometimes use a condom.

— Forty-two percent know people who shoot drugs.

While young people continue to shoot drugs, have unprotected sex, and get pregnant at the same alarming rates as before the advent of the AIDS epidemic, adults on school boards and boards of education are embroiled in emotional, diversionary controversies about sex education—how explicit to be about sex and drugs; whether methods of birth control, which are the only available artificial methods of preventing AIDS, should be discussed, displayed, or distributed.

If we are to ensure the well-being of our children, we must aggressively pursue the education, follow-up education, and, even more importantly, the follow-up counseling of adolescents, who are at the stage in life during which they are least receptive to adult intervention—when they are confronted with adulthood themselves, an adulthood that includes the challenge and excitement of sex and drugs.

If we are to ensure and encourage stable environments and compassionate care for PWAs, we must educate family members and communities to respond to those in need of care. Family case management is critical, but existing informal networks must also be encouraged. Only such steps will help kill the climate of fear about AIDS.

If we are to ensure that those already infected receive the best care, regardless of insurance coverage or class status, we must provide ongoing education to current care givers, create new sources of care givers, and provide respite and support for those providing care.

Because AIDS has disproportionately affected black and Hispanic women and children, future planning must involve the input of black and Hispanic women at the highest levels. We must base care and planning upon the most accurate knowledge and the most creative and promising guesses we can make, while also providing the compassion and coordination of services so lacking now. We must anticipate; we cannot luxuriate in testing the limits of women's endurance. Prevention, yes, and foresight based upon what is happening now. New policy issues will be arising in proportion to new situations, such as the lack of housing for adolescents with AIDS or HIV positivity. In New York City we must develop policy recommendations based upon large minority caseloads in a city torn apart by racism. While we may have the ability, the question is whether we have the will, the will to act immediately — to provide care and services for those already affected/infected and to inform and protect others from contracting this devastating disease.