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AIDS Public Policy: Implications for Families

Elaine A. Anderson, Ph.D.

Much has been written about the AIDS crisis in the past few years. However, relatively little of this discussion has focused on AIDS as it may affect families. This report emerged from the 1987 Groves Conference on Marriage and the Family. It is a version of the chapter on public policy in AIDS and Families *(ed. Eleanor Macklin, Hayworth Press, forthcoming, summer 1988), prepared by the conference's Task Force on AIDS and Families. The book details the probable impact of AIDS on individuals, families, and communities and delineates the implications for relevant professionals, organizations, and public policy. Those individuals who participated in writing portions of the chapter on which this article is based are acknowledged at the end of the article.*

AIDS policymakers at all levels should consider the manner in which their efforts may affect the ability of the family to perform successfully its vital roles and functions. Ideally, policy concerning AIDS should be designed to strengthen and protect the family's contribution, not to debilitate or weaken it.

Because of the stigma attached to the disease, as well as its deadly nature and enormous health care costs, policy concerning AIDS treatment and care has an unusual potential to make a negative impact on the family — to encourage families to cast out those members stricken with the disease, and to generate feelings of distance and alienation among family members.

Professionals who are concerned with the impact of AIDS and AIDS policy on family functioning must ask a critical question: How will the proposed policy affect the ability of the family to carry out its important functions in our society?

Guidelines for AIDS Policymakers

The following guidelines and principles should be employed by persons assessing the potential family impact of any proposed legislation related to AIDS, and should be included in any policy considerations.

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1. Families should be broadly defined to include, besides the traditional biological relationships, those committed relationships between individuals which fulfill the function of family.

2. It must be remembered that the effects of policy concerning AIDS prevention, treatment, and care will be experienced by people whose lives usually have implications for a number of other individuals and groups. Family systems theory considers each family member, and the family as a unit, as parts of a larger interactive social system. This interactive systemic view of society suggests that events and feelings in the life of one family member overlap and influence those of the other family members and in turn affect their ability to perform in other life arenas. AIDS, therefore, has an impact not only on the individual and the family system, but also on the broader emotional, sexual, educational, religious, political, legal, health care, work, and economic systems with which the family and its members intersect.

3. The family may take a variety of forms. No single model of family functioning can be used to gauge the effects of AIDS policies, because no standard prototypical American family exists today. Families differ with respect to religion; locus (urban/rural, region of the country); social class; educational level; ethnicity/race; and numbers of parents, children, and grandparents. Responsible strategies for rural families living with three generations under one roof, for example, may produce undesirable outcomes when applied to low-income, inner-city, single-parent families.

4. The influence of a family member with AIDS reaches across generational and geographic boundaries. People with AIDS may also be parents, children, grandparents, siblings, aunts, uncles, lovers, or teachers; eventually, they will be ancestors. Over time, people move from one family form to another. When they move to a new family form, they may pick up new functions. The changing needs over time, of the individual within each family form, must be reflected in policy.

5. AIDS policies should be designed to strengthen families and foster the support that families can provide. Policy development should be conducted with the intention of calling upon the positive, integrative potentials of American families.

6. AIDS policy should take into account the myriad threats that the disease poses to the stability of the family, and should strive to protect and bolster family durability to address those threats.

7. Families have important functions within a broad continuum of health care related to AIDS. Families are important links in the chain of intervention, whether it be at the level of education and prevention or diagnosis, care, and treatment.

8. The family has a particularly important role in AIDS prevention. Families can teach and encourage preventive strategies.

9. The family's traditional role as caretaker and care giver should be fostered by policies that deal with the care and treatment of people with AIDS. Removing the family from this vital caretaking and care-giving role, or making its cost prohibitive — both emotionally and financially — may result in persons with AIDS becoming wards of the state or additions to the indigent homeless population.

10. AIDS policy should strive to support the integrity of the family. In general, whenever a family is available to a person with AIDS, the plan of choice would be to foster that support with psychosocial and financial assistance. Because providing care to a loved one with AIDS can quickly deplete the resources of a family, policies for care and treatment of AIDS, by augmenting the family's financial and emotional resources, should enable a family to continue to be the major source of care.

11. In addition to responsibilities, families have important rights that need to be protected. The family has the right to participate in decision making regarding such issues as testing, residence, and treatment, as well as the right to privacy, confidentiality, and protection from discrimination and disclosure. These rights will be discussed later in this report.

Any policy decision, on any specific issue, can have an effect on the family. Policy decisions may be made at several levels of policymaking, as follows.

Typically, when one thinks of policymaking, *government policymakers* come to mind. Usually these are federal or state officials. However, policy decisions are made at other levels as well. *Communities make policy* decisions. The school board decides whether or not to close a local school; these same policymakers may review and approve the content of the courses our children are taught. *Professionals* within a range of settings *make policy* decisions. These settings may include our place of work, the businesses we use, or the health facilities we need. Within all of these settings, professionals are making policy decisions that affect the lives of individuals and families. Finally, *families* also make *policy decisions* on how they will run their daily lives. These decisions include such things as what children will be taught within the family, who does what, and how money is spent.

Specific Policy Issues

The following discussion addresses some major policy areas related to AIDS and the family. It is organized around the four levels of policy decision making just discussed: government, community, professional, and family. Only those levels of policy decision making which are most relevant are included in the discussion of each policy area.

Social Science Research

In the relatively short time during which we have been aware of HIV and its linkage to the disease syndrome known as AIDS, significant research has been conducted on the biomedical aspects of the disease. Many important areas of research continue to need support.[1]

The social science research needs that fall within the scope of this report are discussed below.

Government policy. Given the potential magnitude of the impact of HIV, epidemiological research at a national level must be expanded. It is especially important that there be support for the epidemiological studies of "lower risk" populations as well as of the "high risk/higher incidence" groups. Such efforts would facilitate the development of a more complete data base, allowing more accurate predictions of spread of the disease and a better understanding of the etiologic factors involved. This could begin with baseline data collected through recommended voluntary, anonymous testing centers and through anonymous randomized samples in other settings.

An ongoing nationwide study of sexual behavior and epidemiology needs to be established. In recent years, less and less financial support has been provided for researchers to study human sexual behavior and patterns. If we are to develop educational programs to change the sexual behaviors that contribute to the spread of HIV, we must know more about the epidemiology of these behaviors.

More knowledge about the dynamics of human interaction will probably be the cornerstone of any concerted effort to change behavior patterns. Little research has been conducted on the relationship between human behavior, HIV infection, and AIDS. The development of healthy human relationships through the progression of temporary sexual relationships, dating and courtship, and partnering, marriage, and parenting needs to be understood further so that the interaction between HIV infection and changes in the development of relationships and the family can be appreciated.

Also needed is longitudinal research with a life-span perspective. In other words, we do not fully know how the presence of this virus will change the ways in which people seek dating partners and potential lifetime companions or marriage partners. We do not know how this virus will change the prevalence of extramarital affairs, nor do we know how the knowledge of such affairs might affect the well-being and future of a particular marital dyad. Finally, we know little about how AIDS will affect a couple's decision whether to have children. All of these issues, which focus on different stages of relationships and family development, present important questions. Following relationships over the course of time is important in our understanding of human behavior. This information likewise is important in the development of the best educational tools for preventive programs.

In addition, social science research efforts must be enhanced to assess (1) the relationship between stress, depression, the knowledge that an individual has tested HIV-antibody-positive, and the open expression of his or her health status; (2) the effect of the virus on the central nervous system; (3) the relationship between fear and the public's ability to appropriately respond to AIDS; and (4) elimination of the discrimination that often arises when changes in behavior become necessary. Research efforts must emphasize the coordination of the psychosocial and medical needs of the population.

Any discussion identifying prevention as the cornerstone of our current response to AIDS assumes that we have developed the educational programs that can encourage change in behavior. Additional research and development funds are necessary to improve the current educational programs and to promote new programs that will reach target groups and provide the necessary information in an appropriately sensitive manner. Evaluation of effectiveness is important for all social science research, but for AIDS educational programs, it is paramount. AIDS educators should receive both training and evaluation.

A coordinated plan to develop research/treatment programs for persons with AIDS needs to be consistent with the continuum of care concept. It is important to recognize that those persons who test positive for HIV antibodies fall within a continuum of care that is widely inclusive. For example, individuals who have been diagnosed as having AIDS have a different set of health care needs than asymptomatic individuals who have just learned that they are seropositive.

Finally, family impact analysis should be incorporated into our research protocols. Families may be affected in two major ways as a result of AIDS. First, their ability to fulfill the typical functions of most family units may be impaired or altered; second, the structure of the family may change as a consequence of the virus, or different structures of the family may respond to the impact of AIDS in different ways. Policy recommendations must take into account both their intended and unintended consequences for families. Once a sound data base has been established, we will have better information to use in prevention strategies and public education.

Education

Education is currently the most powerful weapon in the war against AIDS. Obstacles to the development of effective treatments and vaccines, as well as the possible discovery of additional viruses related to HIV, make it clear that prevention is essential to the public health. Dramatic reductions in unsafe practices among gay men indicate that people can and do alter their behavior when they are convinced that it is important to do so. For these reasons, an increased commitment of resources to the task of public education is strongly recommended.

Government policy. Effective education requires federal support and funding. Only with greater commitment to education at a national level can standards be established and adequate resources be marshaled to ensure preventive education for all citizens.

A federally supported program should collect the most current scientific information. U.S. government plans to establish a clearinghouse to disseminate this scientific information rapidly and directly to all agencies and organizations requesting it should be supported. This clearinghouse should not function as a censor of unpopular scientific ideas; rather, it should encourage the dissemination of all relevant AIDS-related research.

A federally coordinated and funded effort should be mounted to educate health care professionals and providers, as well as lay providers and informal alternative care givers such as family members, on all AIDS-related issues relevant to their own health and that of their patients — including the emotional impact on the family. Primary and secondary school teachers also must be trained to provide sex education and health education. Such a program must support research and development related to effective teaching and must provide for the establishment and evaluation of a wide range of educational programs.

The following principles are essential to the effectiveness of education programs within a community.

Community policy. All children have a right to be informed adequately so that they can protect their own health and safety. AIDS education should be placed in a context of health and sex education, which should be part of every school curriculum at all levels. It is imperative that children learn about problems such as AIDS within the context of a healthy understanding of sexuality, reproduction, and responsible sexual behavior. Problem-oriented approaches to education can generate new problems. Therefore, a good sex education curriculum for all children should precede education regarding AIDS and other sexually transmitted diseases.

It is essential that love, commitment, trust, honesty, caring, and other similar values be taught. It is important, for example, that students be taught that if they become HIV-infected they should not knowingly infect others. But AIDS should not be used as an excuse to erase the progress made by the "sexual revolution" during the past quarter century. Most Americans are not prepared to return to the sexual repression of an earlier era, and it is urgent that we work to safeguard the healthy advances made in our attitudes toward human sexuality.

Education programs should avoid an antisexual bias. Using AIDS education as justification for promoting such biases presents a number of serious dangers. Foremost among these is the possibility that sexual repression promotes the establishment of relationships in which unsafe sex may be more likely to occur. Furthermore, sexual repression inhibits the development of love, respect, and communication with potential sexual partners. And these are the qualities of relationships which facilitate the practice of safer sex.

AIDS education must be grounded in the latest research on relevant topics. This includes social science and epidemiological research as well as biomedical data. Finally, all education programs should support creativity and innovation. Traditional teaching methods may not be the ones best suited to AIDS education, for a variety of reasons; for example, many at risk may be suspicious of authority or may be functionally illiterate. Individuals affected by AIDS and ARC are often willing to share their experiences and newly gained understanding with young people. A personal connection with individuals who have AIDS, as opposed to the use of abstract teaching materials, is especially powerful in helping people to face their own feelings about AIDS. This in turn may lead to positive, dramatic changes in behavior.

Family policy. Parents should be encouraged to participate in the development and implementation of programs directed at children. Special programs that educate parents should be supported at local, state, and federal levels. Such programs can enable parents to be constructive forces in school programs and can help them to supplement school education with home education. Involving all those who may be affected by AIDS, whether they are parents, schools, or members of high-risk groups, is important in any preventive education program in order to dispel myths, quell fears, and forestall discrimination.

Discrimination

The United States today stands at a crossroad. AIDS is only a part of the total epidemic. Fear, lack of understanding, and bigotry have already caused at least as much disruption in the lives of affected persons as has the disease itself. The by-product of this AIDS-related fear, lack of understanding, and bigotry has been discrimination on virtually all levels against persons with (or perceived to have) AIDS, ARC, or HIV infection.

For example, employers have fired employees who have, or who are suspected of having, AIDS, ARC, or asymptomatic HIV infection. Some employers have required employees to take the HIV antibody test. As AZT and other experimental drugs prolong the life span of persons with AIDS, the number of affected individuals in the workplace will climb rapidly. While a few progressive companies have developed explicit policies protecting the rights of their employees with AIDS, most have not. It is likely that the workplace will become the most prevalent arena for AIDS-related discrimination in the near future.

Landlords have evicted, or sought to evict, persons with AIDS from their homes or apartments. In New York City, it is estimated that hundreds of persons with AIDS or severe ARC are homeless, and are forced to live in shelters, on the streets, in the subways, and in the parks. In such environments, they often become victims of violence, theft, lack of privacy, and multiple opportunistic infections. Some landlords have refused to make repairs or provide essential services, such as heat and hot water, for tenants with AIDS. AIDS service and research organizations have themselves been subject to discrimination on the part of unscrupulous landlords who have refused to rent office space or who have charged exorbitant rents.

Insurance companies have required a negative HIV test result for acceptance among many applicants, have refused to cover treatment costs for persons with AIDS or severe ARC, and have terminated coverage even when the patient had no prior knowledge of his or her HIV infection. Many ambulance and ambulette drivers, physicians, psychiatrists and psychotherapists, dentists, hospital cleaning and food preparation staff, laboratory technicians, and physical therapists have refused to help or assist persons with AIDS. Among nearly five hundred funeral homes, a recent study by the Gay Men's Health Crisis in New York City was able to find only seventy-six that were willing to be listed as accepting deceased persons with AIDS without charging excessive rates.[2]

Perhaps most alarming of all has been the dramatic increase in AIDS-related violence directed against gay men and lesbians. The National Gay and Lesbian Task Force has documented a fourfold increase from 1985 to 1986 in the United States in verbal abuse and threats where AIDS is frequently mentioned and in the overall number of homicides. In that one year, physical assaults increased 64 percent while police-related activity increased 72 percent.[3] Even though much of the violence comes from male teenagers, no school district in the country has initiated an educational campaign to curb it. These varied examples point to the importance of addressing AIDS-related discrimination as it affects the family. It is difficult to develop policies for the benefit of the entire family if one member is suffering from such severe stigmatization.

Government policy. There is a need for a policy on AIDS at the national executive level. That policy should include the strongest possible statement against AIDS-related discrimination in every area. The policy should be highly specific in order to avoid ambiguity, and should ban AIDS-related discrimination in employment, housing, prisons, hospitals, schools, nursing homes, insurance coverage, funeral homes, ambulance and ambulette services, health and mental health care services, day care facilities, and any other area where it might occur. However, until a national policy on AIDS is formulated, all state and municipal governments should develop their own legislation to combat AIDS-related discrimination.

State and municipal human rights commissions should develop an AIDS division that would handle only AIDS-related discrimination cases. An ombudsman should actively evaluate patterns of discrimination in various industries and services, such as funeral homes. This cannot be done unless the budgets for human rights commissions are augmented.

Community policy. Fair housing laws should be amended to address AIDS-related discrimination. Persons with AIDS or HIV infection should not be excluded from renting or purchasing an apartment or house, nor should they be evicted from their premises. Many of these individuals are part of a functional family unit. Discriminating against the person with AIDS or HIV infection also prohibits their loved ones from obtaining suitable housing, or may force a family to separate. Family members and lovers of the deceased should not be evicted from the house or apartment following the death of a person with AIDS. Construction of new housing for homeless persons with AIDS or HIV infection is urgently needed.

Professional policy. Employers should be prohibited from firing, not hiring, or limiting the work of persons with AIDS or HIV infection, provided that such persons can reasonably perform their job. No one should be required to take the HIV antibody test as a condition of ordinary employment, nor should an employer be allowed access to any record indicating that an employee has taken an HIV antibody test — or to the results of such a test. AIDS education workshops should be conducted in the workplace for both management and employees. Sexual orientation or race should not be a presumption of HIV seropositivity, and employment decisions should not be based upon such considerations. The ability of persons with AIDS or HIV infection to provide for themselves economically is important for several reasons. First, being active and busy can positively affect one's mental health. Second, many insurance policies won't cover AIDS-related illness; thus, money is needed to pay the health care bills. Third, many persons with AIDS or HIV infection also have family members who are economically dependent upon them.

The federal government will inevitably have to provide economic assistance through catastrophic health insurance coverage or some co-insurance plan, at least for persons with AIDS or severe ARC. In the meantime, health insurance companies must be prohibited from discriminating on the basis of HIV infection or risk-group membership. They must not be allowed access on any level — governmental or through health care professionals — to HIV antibody test results, and they must not be allowed to require HIV testing for enrollment purposes.

Hospitals and nursing homes should provide compassionate, nondiscriminatory care for persons with AIDS. An ombudsman at each hospital should be appointed to monitor the care of AIDS and severe ARC patients. Hospitals and alternative test sites should create strong links with existing community-based AIDS social service organizations. As with all institutional settings, hospitals and nursing homes should encourage involvement by family members, lovers, and friends of the patient.

Family policy. AIDS-related discrimination has occurred in schools, in prisons, in other institutional settings, and — most poignantly — in the home. For example, the New York City Commission on Human Rights reported that a grandmother called, wanting to know where she could take the HIV antibody test. She had two children: a son who was gay and whose lover had recently died of AIDS, and a married daughter with two children. After the death of her son's lover, the woman had visited her son, and her daughter subsequently refused to allow her to visit her grandchildren, because she feared they would become infected. The woman was heartbroken and wanted to take the HIV antibody test to prove to her daughter that it was safe for her to visit her grandchildren.[4] Fear, lack of understanding, and bigotry often take their greatest toll in the home. The American family, in all its diverse forms, must be supported and strengthened under such adverse conditions.

Treatment

The need for effective delivery of health services to persons with AIDS presents health care policymakers in both the public and private sectors with compelling and difficult challenges. Providing health care to an increasingly debilitated chronic population with a limited life expectancy is an enormously complex task, unprecedented in its capacity to tax our existing system. The issues involved include access to and the appropriate delivery of care and treatment; the recruitment of sufficient and well-trained health care personnel; the provision of adequate numbers of beds in hospitals, long-term care facilities, and other settings; and the underlying, difficult matter of financing this care.

Community policy. It is evident to the health care provider community, including thousands of family professionals in the United States, that the rights, the privacy, and, ultimately, the dignity of persons with AIDS and their families must be respected and manifested. This overarching principle must always be preserved.

Two other important assumptions are made at the outset. First, care and treatment must be provided from a multidisciplinary perspective, using appropriate treatment regimens, biomedical or physiological and psychosocial. Second, an effective and efficient system of care for persons with AIDS must be a coordinated system. For example, care must be integrated between health care programs funded and administered at the local, state, federal, and private-sector levels. Also, care must integrate comprehensive treatment at several levels of service delivery, such as the family unit, the outpatient clinic, the acute care hospital, the extended care facility, and the hospice.

Moreover, medical treatment should be accompanied by care that meets the emotional and psychosocial needs of the person with AIDS and his or her immediate and extended family. For example, housing requirements, employment, and virtually every other system with which the person with AIDS engages must be coordinated at every stage of the illness, with his or her medical needs. These systems change as the illness progresses. Nevertheless, at every stage of the illness, a "systemic" focus must be preserved.

There is an inherent interrelationship between the care and treatment necessary for persons with AIDS and the necessity of providing adequate funds to support this care. The care and treatment that actually are available (and provided) will be determined by available funds. It also is true that the funds that eventually become available will be determined, at least in part, by the need for care and treatment. These issues seem to be circular, and they are. Nonetheless, it is vital for policymakers to tackle this web in a deliberative fashion. The service requirements must dictate the funding that becomes available, rather than the opposite. It would be catastrophic if, in the final analysis, services were determined exclusively by the funds that were available. Thus, a discussion of health care financing for care and treatment of persons with AIDS should be approached from the perspective of the social and medical services that are needed. This inductive approach to policy formation is sensible and serves the public interest.

Professional policy. A network of services for persons with AIDS must be developed and must be integrated to the fullest extent possible within the established health care delivery system. The evolving integrated service delivery must combine the latest biomedical information with an understanding of and sensitivity toward the psychological sequelae of AIDS and ARC. An integrated care system should be staffed by trained health care personnel at every level of the delivery structure, from clerical and support staff to medical staff. They should not only understand the complexities of the AIDS illness pattern, but also be committed to integrate biomedical treatment with psychosocial concerns. One example of a viable conceptual model comes from the burgeoning field of family system medicine. This field integrates both the biomedical and psychosocial with an appreciation of the needs of the family within the context of systems theory. That is, the person with AIDS or ARC is viewed not in isolation from his or her environment, but rather as an active participant influenced by and contributing to the many "subsystems" with which he or she interacts. Another appropriate example is the hospice. Hospice care integrates necessary treatment directed at comforting chronically ill individuals, respects an individual by affirming his or her dignity, and includes an individual's family within the treatment program.

Care and treatment of the person with AIDS or ARC, from this perspective, should take place in the least restrictive and most appropriate setting. A continuum of care setting must also be included in a service delivery plan. The continuum should include, for example, outpatient treatment; partial hospitalization; acute care inpatient settings; after-care facilities; home health care; chronic and long-term care; and hospice care that integrates and coordinates the necessary treatment. AIDS-related care must be provided in a variety of locations.

Many services for persons with AIDS can reasonably be included in outpatient settings. However, as the illness progresses, the continuum of care also must advance to an increasingly acute and then chronic level. It is inevitable that this will be the case for many thousands of persons with AIDS in the years ahead. A service delivery structure must be planned now that will be in place so that the estimated 1.5 million to 2 million Americans who are HIV-positive, a large percentage of whom eventually will manifest some measure of AIDS-related symptoms, will have available to them and to their families the appropriate and necessary care. It is very likely that families will be the site of care for many AIDS patients. We must work now to enable families to provide care in most instances. This challenge is a major imperative to which the health policy community must respond.

Government policy. Governments — local, state, federal, and international — must develop a significantly expanded and targeted health care delivery system for the care and treatment of persons with AIDS. This system must be coordinated with existing health resources in communities. It must be attentive to biomedical developments and sensitive to the psychosocial needs of persons with AIDS and their families, including the right of privacy and confidentiality. The thrust of government-derived health and social policy should be to provide universal access to necessary health services, with regard for the appropriate level of care within a continuum of care. This help should be provided in a nondiscriminatory manner, without consideration of race, sexual orientation, or other criteria affecting civil and human rights and one's ability to pay. Thus, a partnership among business, labor, and government — the private and public sectors — must be formed to ensure that care and treatment are provided.

Considerable discussion and creativity will be entailed in designing an equitable system with sufficient funds to allow for the development and implementation of programs. Certainly, as the prevalence of HIV infection, AIDS, and ARC increases, an evaluation component must also be included within any program. Whichever treatment strategies are selected, they must reflect the varied population at risk, including children, gay men and lesbians, intravenous drug users, and straight women and men.

Children

Policies concerning children with AIDS are particularly complex. All children, by virtue of their age, are dependent and vulnerable. Their parents are presumed to be the natural protectors of their interests. When parents are unable or unwilling to assume this role, others — relatives, court-appointed guardians, social service agencies — must step in. Children at risk of contracting AIDS are in jeopardy in several ways. In the case of perinatal transmission, the mother is by definition infected. If she is not already ill, she is at risk of developing symptoms and eventually dying.

Currently, most cases of perinatal transmission occur in black and Hispanic/Latino mothers.[5] HIV-infected women from these groups are most often either intravenous drug users or the sexual partners of intravenous drug users. They are already bearing the burdens of discrimination and poverty — even without the added weight of HIV infection. Furthermore, in many cases the birth of an infected baby is often the first sign that the mother is infected and that AIDS may already be a threat to family stability. A baby born under these circumstances — infected, perhaps ill, the unwelcome herald of illness in the family, and a member of a group already suffering severe social discrimination — has a poor chance in life.

Articulation of many of the policy issues surrounding children is still on the horizon. Increasing numbers of these children and their families will be affected by policy decisions not yet made. All such decisions must take into account the material and emotional needs of children, the importance of maintaining (wherever possible) a family structure that can support these needs, and adequate social and community services to support the families.

Government policy. At the federal level, sufficient levels of funding should be channeled through state and local agencies to provide needed services. Federal officials can also play a part in reducing fear and stigma by educating the general public about the lack of evidence for casual transmission and the importance of accepting children with AIDS, ARC, or HIV infection in schools and other community settings.

State agencies and city and local governments can play a similar role. They are directly responsible for education, foster care, day care, and health care policies that will affect children and their families. These policies will have to take into account the needs of children and their families, the interests of workers who provide services, and the other funding needs in the community. Local circumstances will dictate specific policies. However, all policies should be designed to fulfill society's obligations to children.

Community policy. Many of the most important policy decisions will occur at the local level. In terms of school attendance, the American Academy of Pediatrics, the U.S. Public Health Service, and the *Surgeon General's Report on Acquired Immune Deficiency Syndrome* stress that casual contact between infected children and their schoolmates is not a risk for AIDS. The surgeon general's report states, "None of the identified cases of AIDS in the United States are known or are suspected to have been transmitted from one child to another in school, day care, or foster care settings."[6] No blanket rules can be made for all school boards to cover all possible cases of children with AIDS, and each case should be considered separately, as would be done with any child with a special problem, such as cerebral palsy or asthma. A good team to make such decisions jointly with the school board would consist of the child's parents and physician and a public health official.[7]

Attendance at day care and placement in foster care present more problems, since infants and preschool-age children do not have the same ability to control behavior and bodily excretions that older children do. However, with adequate staff education and precautions, these children can ordinarily be placed in such settings, as the American Academy of Pediatrics and the Centers for Disease Control suggest.[8] Here too, individualized decision making is central.

Since day care is not a legal right, and since most day care is offered through private institutions and individuals, it is particularly important that governmental agencies monitor the policies of these agencies to make sure that children with AIDS, ARC, or HIV infection are not systematically excluded.

Two problems require particular attention: confidentiality, and consent for testing. Because information about a child's serostatus can have devastating consequences if it becomes known to people other than those who have direct responsibility for the child, special care must be taken to protect confidentiality. The question of who has a legitimate need to know this information must be discussed thoroughly and carefully, with special consideration given to the circumstances that prevail. All those who are deemed to have a need to know must be made aware of their responsibility to keep this information confidential.

Testing for entry to day care raises other issues. Adults are ordinarily given the opportunity to give a voluntary, informed consent to HIV antibody testing. This process includes information about the test and the interpretation of the results, whether they are negative or positive. Parents and guardians should have the same opportunity to give consent for a child, or to decline testing, if they fully understand the reasons that the test may be considered appropriate. Counseling is essential not only for adults who are being tested, but also for those who bear the responsibility for a child's welfare.

Another aspect of consent is the question of whether foster parents should have information about a child's serostatus before they agree to take the child. Practice in this area is divided; some agencies refuse to screen children or to divulge this information to prospective foster parents; others will do so on request. Some foster parents understandably wish to have this information, both in deciding whether to commit their emotional and other resources to a particular child and in planning their own child-care procedures. However, policies should be constructed in ways that will give potential foster parents complete information about risks and outcomes while not unduly discouraging them from taking on this responsibility. At the same time, the issue of liability for a foster care agency must also be considered. Children with AIDS, ARC, or HIV infection are particularly dependent on foster care. This avenue of family support should not be closed to them by virtue of their infection.

If it is impossible to place some children with AIDS, ARC, or HIV infection in foster care, day care, or schools, appropriate alternative facilities must be devised to give such children as normal an existence as possible. However, these alternative facilities should not be considered the first choice for placement.

Professional policy. Professional education and training must include information about pediatric AIDS, ARC, and HIV infection and the most up-to-date treatment and research protocols. Education is particularly important for health care, day care, and other workers who will have direct contact with infected children. The risk of their becoming infected through working with these children is small, but it does exist. Workers must be trained in appropriate infection control measures. In addition, the extraordinary stress of dealing with infected and dying children must be recognized in professional training. Persons who have had experience in pediatric oncology may be able to provide advice to those who are involved in developing appropriate stress reduction and anti-burnout programs.

Family policy. All members of a family are affected when a child has AIDS, ARC, or HIV infection. The birth of such a baby may place a severe strain on a marriage or other relationship. Uninfected siblings may also suffer deprivation and stigmatization, and may worry about their own health or that of their mother or father. The family focus on the infected child may alter family dynamics and functioning. Family members who may be brought into the situation should be aware of these far-reaching effects. Professional family therapy should be available to assist families in adjusting to the situation and in providing the best care for all members of the family.

Risk Reduction

Membership in a risk group does not cause AIDS; risk behaviors do. An HIV-negative male couple who have been together in a monogamous relationship for the past ten years and who do not inject drugs are not at risk for AIDS. Not who you are, but rather what you do and with whom creates the problem.

Government policy. The U.S. Department of Education should take the lead in providing and funding a massive AIDS risk-reduction program directed specifically at the various sociocultural subpopulations throughout the United States. Condoms, spermicides, and literature on AIDS should be made available at no cost or on a sliding-fee scale upon request. Television, radio, newspapers, magazines, and other media should be utilized. The messages should be easily understandable, explicit, and not moralistic. It is the responsibility of the federal government, in concert with state and local officials, to educate the American public about AIDS. Punitive measures, such as quarantine, mandatory HIV antibody testing, and travel restrictions, may only drive persons most at risk for HIV infection underground. Efforts must be made to reduce the stigma of AIDS, not to enhance it.

Community policy. Specifically, the needs of some of those groups who have been most affected must be addressed. The dignity of millions of gay men around the world should be maintained. The families of gay men should be encouraged to become supportive in these most difficult times. State and municipal governments should be encouraged to put an end to AIDS-related discrimination. From the perspective of risk reduction, society should be especially supportive of two gay men living together in a monogamous relationship. It should, however, be kept in mind that monogamy (or abstinence) is not for everyone, and that safer sex practiced with extreme caution with more than one partner is a more responsible alternative than not practicing safe sex with one infected partner.

Prostitution will not be stopped by AIDS, but its risks can be minimized. Prostitutes should be educated about the use of condoms and spermicides during vaginal intercourse, and about refraining from anal sex. Legalization of prostitution, by permitting greater regulation of the practice, would lead to increased safety both for prostitutes and their clients.

Intravenous drug users should be encouraged to stop using drugs. Many more drug rehabilitation centers and methadone programs must be established to meet the demand for treatment. For those who cannot stop shooting drugs or who lack the desire to stop, needles and syringes should be distributed to terminate the practice of sharing "works." "Shooting galleries" — gathering places where drug users congregate to share drugs — should be closed throughout the United States. Intravenous drug users must become better informed about disinfectant practices. More important, the social conditions that lead to intravenous drug use should be improved. Unemployment, illiteracy, poverty, racial discrimination, inadequate housing, and troubled families are underlying causes of widespread intravenous drug use. These social problems must be addressed and corrected.

Persons who are in jails and prisons also are at higher risk for HIV infection. More extensive health and psychosocial therapy must be made available in these institutions. Many of these individuals are part of families to whom they will return. Enhancing health and safety opportunities, as well as the availability of counseling for incarcerated individuals, will also enhance and protect the future care of their family members. Condom distribution in jails and prisons, along with safer sex information, may protect the health of many individuals, as well as their families and society. Increased opportunities for conjugal visits might also decrease the frequency of high-risk sexual behaviors.

Professional policy. Voluntary HIV testing should be encouraged, particularly for (1) individuals who are not practicing strictly safer sex at all times, unless they have been in an exclusively monogamous relationship for at least a decade; (2) women who wish to have a child; and (3) persons for whom not knowing their status has become more anxiety-provoking than knowing for certain would be. It is absolutely essential that HIV testing be anonymous or confidential. A "confidential" HIV test result that is entered onto the named individual's computerized medical file at a hospital, clinic, physician's office, or laboratory is not confidential at all.

It is important that blood and blood products continue to be carefully screened for HIV. Blood should also be screened for HIV-2 and possibly other newly discovered retroviruses. Support services for hemophiliacs and their families are also necessary, since a large percentage of hemophiliacs became infected before blood screening and heat treatment of Factor VIII were introduced. Within this population, adolescent hemophiliacs need special attention. Not only do these adolescents have to be able to cope with their potentially life-threatening health condition, but they also are attempting to handle the normal sexuality concerns of adolescence. Adolescent hemophiliacs and their families need help to address the sex questions of an adolescent in the special context of AIDS for hemophiliacs.

All risk-reduction efforts should be supportive. Family members, lovers, and friends should be encouraged to be involved in all activities affecting the HIV-infected person. All of the aforementioned recommendations should have funds made available for the social services, education, and research essential for their implementation. A well-planned and well-developed financing mechanism must begin to be implemented immediately if we hope to responsibly meet this public health care crisis.

Financing

The impetus for a health care delivery system to assist persons with AIDS and their families must be service delivery needs, not available funds. This principle is particularly important in the design of a health care delivery system for persons with AIDS, where the needs will quickly exceed the available resources. Extending national health benefits for catastrophic coverage regardless of age should be considered. Such an extension would eliminate the necessity for many persons with AIDS or severe ARC to face destitution if inadequately insured. AIDS must be viewed in the context of other diseases and social problems; thus, the broadest solution to the financing question lies in some form of national health insurance. The model for financing discussed in this article is but one among many alternatives.

Government policy. Envisioned as a system for financing the care and treatment of persons with AIDS and their families is a partnership between the private sector, principally through employer-based health benefit programs, and government funding. Evidence increasingly shows that the cost of providing necessary treatment for persons with AIDS is extraordinarily high. AIDS, a long-term illness, becomes chronic and requires substantial, labor-intensive, long-term care. In combination, these factors are very costly. It is likely that the expense of care and treatment for persons with AIDS will become a significant drain on our private-sector health benefit plans, on the government, and even on our entire economy. For example, Scitovsky and Rice estimated that the direct costs of providing health care to persons with AIDS rose from $630 million in 1985 to over $1.1 billion in 1986.[9] The direct costs will continue to rise, so that by 1991 they will exceed $8.5 billion. Economists have estimated that by 1991, *aside from* the staggering medical costs of the illness, the AIDS epidemic will have cost our nation over $55 billion in lost personal income and other such factors.[10] Now is the time for both private industry and our government to design financing projects that will provide necessary funds at the required fiscal levels.

Private-sector health benefit plans, whenever available, should provide coverage for persons with AIDS, but this cannot be the exclusive coverage. Ten to 15 percent of the U.S. population — 37 million Americans — are covered by individual and small group insurance plans; another 37 million have no health insurance at all.[11] These two groups represent a disproportionate number of persons at high risk for AIDS. Intravenous drug users often are uninsured, and many members of the gay male community appear to be self-employed, therefore more likely to be enrolled in individual or small group plans and subject to stricter underwriting criteria. Health benefit plans should not discriminate against persons with AIDS or HIV infection by denying or limiting coverage. Rather, private-sector plans must continue to provide coverage to the limits of their allowed benefit structures, with the federal government providing a re-insurance or "stop-loss" form of backup protection. In the partnership that is envisioned here, the government would invest in the care and treatment of persons with AIDS or HIV infection, yet not assume the entire financial burden for these services. Some policymakers are suggesting that there be a federally mandated "tax" on health benefit premiums to provide funds to assist with the financing of needed services for persons with AIDS or ARC. Consideration should be given this idea, with appropriate regard for the rights, privacy, and dignity of persons with AIDS or ARC. It may be a viable approach to the issue of financing.

The political context within the Congress, with which the current discussion rests, must be the now popular notion of catastrophic health insurance. During the 100th Congress, proposals have been debated to create a catastrophic program for the nation's largest health benefits program, Medicare. It is entirely appropriate for the question of care and treatment of persons with AIDS or ARC to be linked to this concept, if not to the specific proposals that are being considered.

Catastrophic health coverage is designed to insure an individual and his or her family for serious and costly events beyond their control — events that they could not predict, such as a serious illness requiring lengthy hospitalization and long-term care. This is the situation with AIDS. Advocates support the development of a system of catastrophic care coverage which includes persons with AIDS or ARC. The system envisioned would be parallel to the hospice program, a system of care for terminally ill patients which was affirmed by Congress in recent years and which is now included within the benefit structure of Medicare. However, a health care financing program for persons with AIDS need not be included within Medicare. This is a possible structure, yet other structures should be considered by the Congress, the federal Health Care Financing Administration, and other institutions.

Recognizing that many persons with AIDS do not have insurance, the federal government, in partnership with private industry and local and state governments, should initiate and fund a program that would reflect level of need yet permit autonomy in the selection of health care services. Assuming that treatment protocols will increasingly become standardized, and that the number of experimental procedures will increase, persons with AIDS or HIV infection must remain free to choose from whom and where they wish to receive health care services. With a voucher system, a person with AIDS or ARC could take his or her benefit to any government-sanctioned treatment setting.

In this model, a person with AIDS or ARC who had insurance would first need to use and exhaust all benefits provided through his or her own private health benefits program. It is possible that the government would, in a yet undetermined manner, assist by subsidizing such care. This would be the "means test" component of the program: the use of available benefits. In addition, there should be some mechanism for co-payment by an individual who has sufficient resources to afford a reasonable co-payment. However, it is not recommended that a co-payment provision become a part of any means test if such a provision is to become a deterrent or barrier to care and treatment.

Therefore, the central part of a program to finance and provide care and treatment for persons with AIDS or ARC would be coordinated and heavily funded by the federal government, with some assistance from both state and local governments. The most effective system might be one in which the federal government would develop and then apply a series of criteria for different levels within appropriate continuum of care settings providing care and treatment for persons with AIDS or HIV infection. At each level of a continuum of care, appropriate criteria would be developed. This process must involve input from all of the relevant constituencies, including both consumers (persons with AIDS or HIV infection and their families) and health care providers. Care for persons with AIDS or ARC must be systemically integrated within the established health care delivery system. Standards must be developed to guarantee that those settings providing care to persons with AIDS or HIV infection have the facilities and staff available to provide necessary services of the very highest quality. A network of service delivery settings throughout the nation may evolve which has met federally sanctioned criteria for providing care and treatment to persons with AIDS or ARC. It is probable that most of the needed facilities already exist. These extant facilities can be combined with newly developed facilities to form the federally sanctioned, but not federally administered or directly controlled, settings. This plan is parallel to the federal approval program qualifying hospitals to receive reimbursement from the Medicare program.

Such a system would be expensive to develop and administer. It would, however, provide a framework for a collaborative system of care that could be positioned over the next few years to meet the needs of persons with AIDS or ARC. It would allow for universal access to care. However, there are problems with the design. First, a bureaucratic superstructure would be created. Also, this type of reimbursement structure would be complex, with funding based on chronicity and factors relevant to actual costs of care at different developmental stages of the virus. Moreover, given the size and complexity of such a structure, confidentiality would be difficult, but not impossible, to maintain. Further, this model could unintentionally create a network of AIDS and HIV infection treatment centers that would suffer from discrimination of many types.

Despite these possible criticisms, it is a fundamental responsibility of government to assure the availability of and access to necessary and appropriate health care services. The model described provides a vehicle for the federal government to fulfill its responsibility of providing needed health care services for persons with AIDS or ARC. Neither private industry nor government alone can carry the burden.

Summary

Sufficient fiscal resources must be made available by federal and state government, together with private-sector services, to fund necessary research, education, and training. Therefore, funds must be made available to continue basic and applied research, including both biomedical and psychosocial research, with appropriate attention to social and behavioral science. It would be a tragic error for social and behavioral science research to be sacrificed in favor of biomedical research. Both perspectives of inquiry are necessary.

Funding for education and training must include targeted efforts directed at three groups: individuals at high risk; professionals who may become involved with the care and treatment of persons with AIDS; and the general public. Educational and training efforts must be systematically developed and well funded. Prevention, through careful practices or elimination of high-risk behaviors, could slow the spread of the epidemic. Proper education and training offer our best chance at prevention. These tasks collectively — research, education, and training — must be funded through both existing programs of support and newly developed programs. Funds should be made available from both the public and private sectors. ❧

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Notes

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10. Ibid.
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"When I was first diagnosed, I was very worried about what my family was going to think, my friends, just people in general, and I was real sad and guilty and then I thought, you know, who is the most important person, you know, is it the president, is it Mother Teresa, is it the pope? It's not. It's yourself. Each individual person. There's no reason why you should be alive unless you're the most important person in the world to yourself. And you've got to live your life accordingly and enjoy it to the fullest or it's not worth living."