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AIDS Discrimination: Its Nature, Meaning and Function

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Abstract

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KEYWORDS: AIDS, discrimination, nature

AIDS Discrimination: Its Nature, Meaning and Function*

David I. Schulman**

AIDS is like a stain on a microscopic slide, highlighting pre-existing chronic social problems the way a stain brings into sharp relief the characteristics of certain organisms. For those resistant to confronting such problems — drug abuse or inequitable health care delivery, for example — there is a temptation to attribute them to AIDS, as if our resolution of these issues had been effective until AIDS destroyed our social stability.

AIDS discrimination laws prohibit people from treating AIDS as an exception to all social norms, as the cause of social ills it merely exacerbates. The policy crises surrounding AIDS may force society to adjust those norms. But AIDS discrimination laws require that society adjust all like behavior equally, not merely single AIDS out for exception.

Epidemics threaten the ties that bind communities together, driv-

* This Article is an expanded version of written testimony submitted to the Presidential Commission on the Human Immunodeficiency Virus Epidemic on March 16, 1988 during hearings held by the Commission at Vanderbilt University in Nashville, Tennessee.

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The author, the nation's first full-time government AIDS discrimination attorney, heads the AIDS Discrimination Unit in the office of Los Angeles City Attorney James K. Hahn. Shortly after the author's appointment in January 1986, Norman Nickens and Mitchell Karp were asked by the San Francisco and New York City human rights commissions, respectively, to head similar units. On March 27, 1987, Mr. Nickens, Mr. Karp and the author discussed their work at a panel discussion at the National Lesbian and Gay Health Conference in Los Angeles, California. On June 5, 1987, Mr. Nickens and the author presented a paper co-authored with Mr. Karp at the Third International Conference on AIDS in Washington, D.C.

Benjamin Schatz, head of the AIDS Civil Rights Project (San Francisco), and Richard Robertson, AIDS Coordinator, Office for Civil Rights, United States Department of Health and Human Services (San Francisco) both were appointed to their positions in 1985. However, their activities will not be discussed in detail, since the lessons to be drawn from the work of advocacy groups and large state and federal agencies are beyond the scope of this Article. See *infra*, section II.C.

ing societies to victimize some to bind back together the rest. Yet law can help overcome this ancient human impulse to fracture in times of crisis. This Article examines several ways to do just that regarding AIDS.

It first discusses the nature of AIDS discrimination and draws lessons from the work of those first charged with enforcing AIDS discrimination laws. It then briefly examines two emerging AIDS legal issues, the special problems posed by recalcitrant HIV-infected individuals who knowingly place others at unreasonable risk of infection, and the problems presented by those who are both infected with HIV and mentally ill. The Article then comments upon the role of law in fashioning effective AIDS education programs.

This Article concludes, in the section entitled "The Threat of AIDS Euthanasia," with an analysis of the potential impact of AIDS upon health care delivery. It examines the depersonalizing nature of institutionally-based chronic care and proposes a new public-private partnership to combat its effects, a partnership designed to deinstitutionalize chronic care.

Throughout the Article, the underlying theme is the importance of looking clearly and in new ways at the challenges which lie before us in responding fully and humanly to AIDS.

I. The Nature of AIDS Discrimination¹

AIDS discrimination is like other forms of discrimination familiar to Americans insofar as it is the unfair treatment of individuals based upon irrational fears and prejudices about groups. However, since AIDS discrimination varies in unique respects from other types of discrimination, its character must be carefully examined and new efforts created to overcome its particular divisive and destructive effects.

American society has learned that deeply embedded prejudices against race, for example, are difficult to alter by education alone; they usually require new, positive life experiences, as well before such attitudes change. But, Los Angeles', New York's and San Francisco's AIDS discrimination units have discovered that prejudices against people with AIDS can be dramatically reversed with education about the

1. I owe a great deal to Professor St. Clair Drake for my insights into the general nature of prejudice. Professor Drake is the co-author (with Horace Cayton) of the landmark study of black urban life, *BLACK METROPOLIS: A STUDY OF NEGRO LIFE IN A NORTHERN CITY*.

medical facts of AIDS. However, the staff of these units have also learned about the immense fears about AIDS which block comprehension of the basic medical facts. They have learned that fears about AIDS as a disease and AIDS as the harbinger of social disorder must be addressed before the fight against AIDS discrimination can be truly successful.

A. Fear of the Disease

The fear of AIDS as a disease is five-fold. Each expresses a powerful social taboo which, by its very nature, must be overcome since taboos protect individuals from deep-seated fears.²

The first fear concerns human sexuality. American society's difficulty in public discussion about sexual matters is signalled by the continued lack of consensus about the content of sexual education in the public schools despite thirty years' debate. It is, of course, also signalled by the deep divisions in the nation over gay rights. Yet learning the medical facts necessary to halt HIV's spread requires frank public discussion about sexual activities.

The second fear involves stigma.³ It is one of the cruelest ironies of the epidemic that its impact is greatest among those already stigmatized: gay men and intravenous drug abusers (many of whom are black or brown).⁴ Labeling some groups dangerous, unclean or aberrant functions to externalize what is feared by the normative group.

2. See generally, M. DOUGLAS, *PURITY AND DANGER: AN ANALYSIS OF CONCEPTS OF POLLUTION AND TABOO* (1966); V. TURNER, *THE RITUAL PROCESS: STRUCTURE AND ANTI-STRUCTURE* (1969); and R. Adler, *Tum'ah and Taharah: Ends and Beginnings*, *THE JEWISH WOMAN* (1976).

3. For the classic work on the subject of stigma, see, E. GOFFMAN, *STIGMA: NOTES ON THE MANAGEMENT OF SPOILED IDENTITY* (1963). For a survey of racial minority issues, see AIDS Discrimination Unit, New York City Commission on Human Rights, *AIDS and People of Color: The Discriminatory Impact* (Nov. 13, 1986); N. Nickens, Nat'l Minority AIDS Council Report on AIDS and Ethnic Minorities (available from M. Nickens, 744 Fell St., San Francisco, CA 94117); and Martinez, *AIDS: The Crisis in Latino L.A.*, *L. A. WEEKLY*, October 30-November 5, 1987, at 10. For a provocative and disturbing account of gay issues of stigma, see Mohr, *AIDS, Gay Life, State Coercion*, 6 *RARITAN* (1986). For a discussion of AIDS, stigma and euthanasia, see *infra*, section VI.

4. It is useful in this regard to consider how our response to AIDS might have been different had the epidemic broken out among white, middle-class, happily married mid-Western businessmen or examine our response to the small outbreak of Legionnaires' disease.

Projecting what is feared outside the normative social group strengthens its social bonds during times of social crisis, such as epidemics, when those bonds are threatened. It does so, however, at the expense of the non-normative groups. In a democratic society, where equal rights are guaranteed for all, this primal impulse to stigmatize presents a tremendous challenge, for neither stigmatizing nor the wholesale isolation of others halted the spread of bubonic plague, leprosy or syphilis, and there is no reason to believe that it would halt the spread of AIDS.⁵

Worse, stigmatizing others obstructs the social cooperation necessary to control the epidemic's further spread; infected people identified as "them" and treated punitively naturally become less willing to contribute voluntarily to the social efforts needed for control.⁶ The majority group's disapproval of stigmatized groups' characteristics and habits also obstructs the delivery of education necessary to halt spread of the virus among these groups. People of color, for instance, have complained that AIDS education efforts are often ineffective because, by ignoring crucial cultural differences, they impede those at risk from effectively comprehending and utilizing the information.

For example, too many efforts have relied heavily on written material despite the high illiteracy rates among blacks and Hispanics. Too little material has been available in Spanish. Material directed at gays cannot educate about stopping HIV's spread if it is predicated on the assumption that gays should not be gays. Fear of stigmatized groups, then, intensifies the epidemic through its divisiveness at a time when social cooperation is essential.

The third fear is the fear of being helpless. Despite government entitlement programs, many continue to presume that people should take care of themselves and that families and communities should take care of their own. Yet despite the persistent nature of this presumption,⁷ society's sense of community has eroded, so that when people do need each other when they become sick, truly human caring is difficult

5. For an authoritative discussion of past public health measures and their appropriateness for the AIDS epidemic, see Brandt, *AIDS: From Social History to Public Policy*, 14 LAW, MED. & HEALTH CARE 5-6 (1986) at 231.

6. See *infra*, section III.

7. For a discussion of the nature of the American character, see R. BELLAH, R. MADSEN, W. SULLIVAN & A. TIPTON, *HABITS OF THE HEART: INDIVIDUALISM AND COMMITMENT IN AMERICAN LIFE* (1985). For a discussion of the importance of character in culture, see A. MACINTYRE, *AFTER VIRTUE: A STUDY IN MORAL THEORY* (2d ed. 1984).

to arrange. Yet AIDS demands that society create new ways to mobilize communities' capacity to provide care, comfort and medical treatment,⁸ especially since the emerging AIDS treatment modalities like AZT will prolong the lives of those who are ill but, tragically, exacerbate the epidemic's growing numbers.

The fourth fear concerns mental illness. Society has never resolved its ambivalence and fears about the mentally ill. Yet AIDS potentially will create vast numbers of HIV-demented individuals requiring care from mental health care systems, exacerbated, as well, by the accomplishments of medical treatment modalities.⁹

The fifth fear — death — has always, of course, been the most overwhelming. Yet death has uniquely modern overlays which make it even more difficult to think or talk about today. Death was once part of everyday life, a family and communal event regularly witnessed by everyone. With modern medicine's advances, however, it has been removed to specialized institutions. Experts care for the dying. Experts bury the dead. Most Americans never see a corpse except in carefully cosmeticized viewings before burial.

Whereas death used to occur rapidly from illness, accident, old age or assault, today's medical prowess prolongs life until death occurs slowly, in increasingly debilitating stages. Since infections can now be fought off with antibiotics, it is slow, lingering death, isolated from community and family, ministered by technically competent professionals, which Americans dread. As society's response to death becomes increasingly phobic, so, too, is the response to those infected with an incurable, invariably fatal disease. They force, after all, an unwelcome recognition of one's own mortality, with its anticipation of a comfortless death.

B. *Fear of Social Disorder*

The fear of social disorder can be as primal as the fear of death, for it is the fear of chaos. Epidemics can obstruct or even halt the normal functioning of society. Afflicted people drop out of the work force, removing their economic contributions from society. At the same time, they strain societal resources for they need medical care, food, shelter and companionship.

As more and more places fall empty in the social structure, pan-

8. See *infra*, section VI. D.

9. See *infra*, section IV.

icked people place their individual survival needs over the social obligation to cooperate with others: social relationships collapse, people abandon relatives, there is mass hysteria and mob looting.¹⁰

In all times past, when disorder and panic threatened the ties that bind, law and force were used to blame, isolate and scapegoat the stigmatized to bind together the normative group. Focusing social panic onto already stigmatized groups is an ancient and primary response. America's national character reflected this shameful impulse as recently as World War II when the United States Supreme Court upheld the scapegoating and isolating of Japanese-Americans as a means of dealing with our fear of war.¹¹

Civil rights thinking, however, has evolved since the Second World War. That development is not the product of "special interests" intent upon fracturing the whole, as some suggest. Rather, America's maturing understanding of civil rights is a remarkable bulwark today against the ancient impulse to victimize others; these recent advancements are as remarkable and critical for enabling America to withstand the impact of AIDS as are recent advancements in science.

Civil rights will not provide easy answers to the agonizing policy questions presented by AIDS. But civil rights cannot "give way" to the "demands" of public health, as some insist, for both civil rights and public health laws seek to ensure the vitality of the body politic.

Since the great racial struggles began thirty-five years ago, civil rights law has become a process which teaches Americans how to be civil, even when they are frightened, indeed, especially when they are frightened. Events such as AIDS remind people of epidemics past, of battles of each against all for scarce resources, of how, as Camus observed, ". . . officialdom can never cope with something really catastrophic."¹²

But today, for the first time, civil rights reminds American society of something else.¹³ An archaic form of the word "remember" is "re-member," to bring all members back into the whole. Civil rights enable American citizens to re-member those who are unpopular, those

10. See W. McNEILL, *PLAGUES AND PEOPLE* (1976).

11. *Korematsu v. U.S.*, 319 U.S. 432; 87 L.Ed. 1497; 63 S.Ct. 1124 (1943).

12. A. CAMUS, *THE PLAGUE* 117-118 (1972).

13. The recent Bork hearings demonstrated how thoroughly embedded into the fabric of society the civil rights transformation has become. Southern Democratic senators explained their "no" votes by declaring that their constituents would not tolerate a constitutional re-examination of the new values forged in the civil rights struggles.

who are disenfranchised, even those who are frightening, remember that in a democratic society all are members of the whole.

II. AIDS Discrimination Laws

A. Introduction

Randy Shilts, in his landmark study of the early years of AIDS in America, marked the end of the epidemic's first great cultural wave with Rock Hudson's announcement that he had the disease in July 1985.¹⁴ One month later, Los Angeles City Councilmember Joel Wachs successfully led a drive to enact the nation's first AIDS discrimination measure, undoubtedly aided by the favorable climate created by the movie star's announcement. Los Angeles' new law,¹⁵ passed unanimously by the City Council, began AIDS' second great cultural wave, that of policy-based responses to the epidemic.¹⁶

The national impact of the council's action was immediate and widespread. Network news programs covered the event and the *New York Times* endorsed the measure.¹⁷ The Los Angeles City Attorney's Office, given enforcement powers under the ordinance, was flooded with complaints under the new law and complaints about the new law. Letters to the editor appeared in the local press reflecting elation at the enlightened action of the council and terror at the prospect that the new law would force thousands to be exposed unwillingly to the disease.¹⁸

Los Angeles' law was the first statute to provide clear and unambiguous discrimination protection for people infected with the AIDS virus (HIV). Many attorneys had already anticipated that the analytical concepts of physical handicap rights law applied well to the dilemmas presented by HIV. In fact, litigation was already underway to determine whether people with AIDS were to be included within California's housing and physical handicap rights protections at the

14. RANDY SHILTS, *AND THE BAND PLAYED ON: POLITICS, PEOPLE AND THE AIDS EPIDEMIC* (1987), p. 585.

15. L.A. MUN. CODE section 45.80 *et. seq.*

16. For example, the first bi-weekly newsletter devoted solely to these matters, *AIDS, POLICY & LAW*, began six months later. See Oliver, *AIDS: An Uncharted Legal Field*, *LOS ANGELES TIMES*, April 3, 1986, part 1, p. 1.

17. Editorial, *The Only Weapon Against AIDS*, *NEW YORK TIMES*, August 18, 1985, section 4, p.18.

18. *Letters to the Times*, *LOS ANGELES TIMES*, August 26, 1985, part 2, p.4.

time of the council's action.¹⁹

Los Angeles' action provided critical leadership at a time when no other legislative or executive body was prepared to enact into law what scientists had known for sometime, that HIV could not be casually transmitted.

Normally, legal measures regarding epidemics emanate from the federal government, reflecting the widespread nature of an epidemic. It is emblematic of the madness of the social phenomenon surrounding AIDS, however, that the process was reversed — a municipal government first incorporated scientific knowledge into social policy.²⁰

B. Structure²¹

Los Angeles officials wisely fashioned their ordinance upon familiar principles of physical handicap law, for this enabled attorneys unfamiliar with the arcana of HIV to share a familiar vocabulary — *reasonable accommodation, otherwise qualified, bona fide occupational qualification* — no small comfort when first confronting the tidal wave impact of AIDS upon law. It also enabled citizens to recognize the council's action within a familiar social framework.

In the months that followed Los Angeles' action, four California cities followed suit.²² Since then, many states have re-interpreted their physical handicap protections to include people with AIDS and a number of additional cities in California and elsewhere have passed AIDS-specific statutes. Most importantly, a series of federal court rulings have held AIDS to be a protected handicap under federal law.²³

AIDS discrimination laws, whether AIDS-specific or part of a

19. California Department of Fair Employment and Housing v. Raytheon Company (*Real Party Interest* John Chadbourne), FEHC Dec. No. 87-04.

20. Cf., M. FOUCAULT, MADNESS AND CIVILIZATION: A HISTORY OF INSANITY IN THE AGE OF REASON (1965).

21. For an excellent general introduction, see *Law, Social Policy and Contagious Disease: A Symposium on Acquired Immune Deficiency Syndrome (AIDS)*, 14 Hofstra L. Rev. 1 (1985), especially Leonard, *AIDS and Employment Law Revisited*, *id.* at 11 and Dolgin, *AIDS: Social Meanings and Legal Ramifications*, *id.* at 193.

22. West Hollywood, Berkeley, Oakland and San Francisco.

23. *School Board of Nassau County v. Arline*, 107 S.Ct. 1913 (1987) (holding that persons with contagious diseases are protected by the physical handicap civil rights provisions of the Federal Rehabilitation Act of 1973); *Chalk v. U.S. District Court (Orange County Dept. of Education, real party in interest)*, 840 F.2d 701 (9th Cir. 1988) (holding that *Arline* protects people with AIDS); and *Thomas v. Atascadero Unified School District*, 662 F. Supp. 376 (C.D. Cal. 1987).

general physical handicap scheme, are similarly structured. Besides people infected with HIV, they usually protect people wrongly thought to be infected with HIV, since handicapped rights protections are intended to prohibit the irrational injury of any individual because of prejudice about physical disabilities. The classic example involves people recovered from cancer. Such people fortunately are no longer handicapped. However, irrational employers frightened of cancer might still wish to discriminate against them were they not entitled to handicapped rights protections.

So too, AIDS discrimination laws protect people who might be associated with irrational fears about AIDS, people like family members, care-givers, and gay men. The widow of a man who died of AIDS only agreed to appear on television to discuss the prejudice she and her husband had faced when the producers of the program arranged for her to be filmed in shadow and allowed her to use a pseudonym.²⁴ This widow, although uninfected, is entitled to the full range of protections afforded by laws such as Los Angeles' should she continue to suffer further discrimination.

The forerunner of Los Angeles' law were the physical handicap civil rights protections of the Federal Rehabilitation Act of 1973, enacted by Congress at the end of the activist civil rights era, after the racial struggles and the beginnings of the women's movement. Most states soon followed Congress' action with similar statutes regarding private employment, housing, public accommodations,²⁵ and state government activity.²⁶ Los Angeles' AIDS discrimination law, and all other AIDS-specific statutes and executive orders which followed, drew directly upon the constitutional framework of these earlier physical handicap protections.

That framework established the fundamental assumption that society wished to treat people in decisions about jobs and services as free individuals, unimpaired by others' irrational beliefs and attitudes. Physical handicap laws and their sub-set, AIDS discrimination laws, require that decisions must be based upon sound medical evidence applied in a fair and equal manner. Professors Larry Gostin and William Curran,

24. *Hour Magazine*, (FOX TELEVISION broadcast Sept. 18, 1987).

25. Contrary to the apparent common meaning of the term, "public accommodations" in a legal context is a term of art used to describe the broad ambit of civil life — retail establishments, restaurants, medical and dental services, motels and hotels, theaters, parks, etc.

26. See Leonard, *supra* at note 21.

Harvard School of Public Health, have recently considered the level of scrutiny courts should apply in weighing and balancing the rights these laws create and the duties public health measures entail.²⁷

Gostin and Curran argue that scientific and constitutional understandings have sharpened considerably since the early part of the century, (when most current public health statutes and rulings were formulated). Originally, only a rational basis was necessary for a public health statute to pass constitutional muster, for the power to regulate public health was understood to emanate from the police powers of the state to ensure safety and security. Even by the turn of the century, however, courts had already begun to scrutinize much more closely both the scientific basis for the statute and the appropriateness of the methods to be used to achieve its end. The case of *Jew Ho v. Williamson*²⁸ is illustrative.

Plague broke out in the Chinatown area of San Francisco. The authorities imposed a quarantine around the region, a rational measure to control the epidemic's spread. However, the exact boundaries drawn by San Francisco's public health officials were gerrymandered to include the homes of Chinese residents living outside the area of outbreak and to exclude the homes of caucasians living within the area. The health authorities argued that this action was rational, given the likely associational patterns involved in transmission. The *Jew Ho* court held, however, that this argument was insufficient to justify the level of government intrusion imposed by quarantine.

Gostin and Curran argue that courts today should impose a heightened level of scrutiny to determine the constitutionality of public health measures which affect constitutional or statutorily defined rights. Such measures must not be justified merely by the importance of achieving a public health end. Because public health measures interfere with fundamental rights — such as the right to associate freely and to maintain privacy, measures which also ensure a healthy body politic — such measures today need to have ends and means that fit tightly.

No one would argue, however, that civil rights protections should

27. W. J. CURRAN, L. GOSTIN AND M. CLARK, *ACQUIRED IMMUNE DEFICIENCY SYNDROME: LEGAL AND REGULATORY POLICY* (1986); Gostin and Curran, *Public Health and the Law*, 77 *AMERICAN JOURNAL OF PUBLIC HEALTH* 2 at 214 (1987). For an excellent review of Curran and Gostin's book, see Rosoff, *The AIDS Crisis: Constitutional Turning Point?*, 15 *LAW, MED. & HEALTH CARE* 1-2 (1987) at 80.

28. 103 F. 10 (C.C. N.D. Cal. 1900).

sanction unsafe situations; such laws must never give one the right to place others at unreasonable risk to their health.²⁹ What is critical, however, is the rationality of the analysis. When the burden on others to protect themselves from infection is minimal — as in the case of blood-borne infectious agents such as HIV — then one should not refuse to take those precautions and insist, instead, upon imposing more onerous burdens on those infected.³⁰

When the burden on others to protect themselves from infection is unreasonable — as in the case of airborne agents, which would require that everyone wear masks all the time to avoid exposure — then one may burden those infected, even to the extent of restricting their freedoms. Los Angeles demonstrated this commitment to balancing when it amended its law in June 1986³¹ to incorporate the workplace guidelines,³² issued by the federal government's Centers for Disease Control three months after the law's enactment, to provide guidelines for risk prevention in the workplace.

AIDS discrimination laws hold that if people infected with HIV merely present health threats others can reasonably avoid, then the burden is on others to take those precautions, rather than violate infected people's fundamental rights. If HIV-infected individuals are otherwise physically capable of continuing to perform their jobs, they have a right to keep working.

The test for continued suitability of employment, as in all physical handicap rights contexts, is whether the person with HIV is *otherwise qualified* to perform the task. For example, an individual in a wheelchair who can still type and answer phones has a right to continue working as a secretary. Employers or service providers must *reasonably accommodate* the special needs created by the handicap. They cannot say, "You are fired because your chair won't fit behind the desk;" they have the duty to move the desk away from the wall. However, musical directors need not cancel their tap dance numbers. Being able to tap dance is a *bona fide occupational qualification* of that particular job; people in wheelchairs are not *otherwise qualified* to tap dance.

29. Cf. L.A. MUN. CODE section 45.93(B). In *Arline, supra*, note 23, the matter was referred back to the trial court for a determination of the risk Mrs. Arline's infectious tuberculosis presented to others (having held in its decision only that she was entitled to the due process provisions of the Federal Rehabilitation Act).

30. For a further discussion of reasonable precautions to prevent HIV transmission in the workplace, see *infra*, section V.

31. L.A. MUN. CODE section 45.93(B)(2).

32. 34 MORBIDITY & MORTALITY WEEKLY REPORT (1985) at 681.

If HIV-infected people begin to perform their jobs poorly, they are to be judged by the standards we use to judge others who begin to perform their jobs poorly. Perhaps they should be transferred to less demanding positions. Perhaps they should be re-trained. Perhaps they should be warned about poor performance, with review rights and appeals. But it is important to remember that we already have guidelines and standards for dealing with people whose job performance deteriorates. Individuals divorce, abuse alcohol or drugs, suffer from Alzheimer's and other diseases. Discrimination laws insist that we treat HIV-infected people similarly to others in similar positions. If HIV-infected individuals require reasonable accommodation, then we must accord them the same rights and privileges we accord others who require reasonable accommodation such as permission to work at home or flexible hours to accommodate changes in energy level.

The inclination, however, is to treat AIDS as a special case, an exception to the rule. A nursing director at a medical center said she allowed pregnant nurses to opt out of treating HIV patients. "This was not discriminatory, however, HIV-infected patients are at high risk for cytomegalovirus (CMV). Pregnant nurses should avoid exposure to CMV. Therefore, it is rational to let them opt out of HIV care." She was asked "Do they have the same right to opt out of pediatrics care? Isn't it true that there is an equally high prevalence of CMV among children?" The nurses did not have a similar right. The seemingly rational basis of CMV risk masked the irrational fear of providing care for people with HIV. It might be reasonable to argue that pregnant nurses should not work with either HIV-infected people or sick children. But it is not reasonable to have a policy which excuses them from one population and not the other.

C. Remedies and Enforcement

AIDS discrimination laws provide for traditional discrimination remedies. Injunctive court orders can be sought by city attorneys and by private attorneys to halt discriminatory practices.³³ Private attorneys can seek damages for their clients to recompense for injury, but city attorneys cannot.³⁴

33. In New York and San Francisco, the human rights commissions investigate and mediate, and request city attorney action on appropriate cases. In Los Angeles, the City Attorney's Office fulfills all three functions.

34. This exclusion is based upon the general principle that it is inappropriate to

Early in the Los Angeles City Attorney's experience with the new law, the need to develop non-traditional methods of enforcement was soon recognized.³⁵ Initially, four deputy city attorneys with full-time assignments elsewhere handled inquiries and complaints on their over-time. They reviewed over fifty discrimination complaints and began to forge a philosophy of early intervention and mediation. One case demonstrated the importance of prohibiting discrimination even against people who are not infected. A local health club attempted to refund the membership fee of a skinny gay member (who it turned out, was not infected) because of pressure from other club members. They were concerned that since he was skinny and gay, he must have "it". Through early intervention and education, the City Attorney's Office was able to resolve the case without litigation.

These volunteer attorneys eventually determined, however, that they did not have the time to develop the technical expertise necessary to address the myriad questions being posed, particularly the core questions about virus transmission. In December 1985, the City Attorney successfully sought the creation of a full-time deputy city attorney position to enforce the new law.

During my first six months, I reviewed fifty-three complaints, held three hearings, responded to fifty-eight community and professional inquiries and twenty-three media contacts, attended thirty-six professional or community meetings, and spoke to nineteen groups, including the Los Angeles County Medical Association, the Gay and Lesbian Chapter of the ACLU of Southern California, the Screen Actors Guild, and to community and professional representatives of the Hispanic community. Our office assisted the California Continuing Education of the Bar Institute to create two-day AIDS and law conferences for lawyers. During my first full year, I reviewed ninety-three complaints, held five hearings, handled one hundred and twenty community and professional inquiries, responded to forty-eight media contacts, attended seventy-five meetings and spoke to forty different groups.

During the first five months of my second year, the number of

use taxpayer money to assist private citizens to recover money damages. It is thought that contingent fees in damage cases creates sufficient incentive for private attorneys to take such cases. It is thought appropriate, however, for government attorneys to seek court orders to halt discriminatory behavior because such actions create a healthier climate for everyone and may not include the monetary award necessary to make it economically feasible for private attorneys to seek them.

35. See *supra*, section I.

complaints fell by almost half to twenty-four and I held only one hearing, but the number of community and professional inquiries more than doubled to one hundred and five. The number of media contacts (twenty-six) remained about the same, the number of meetings dropped (twenty-five), and the number of speaking engagements increased to twenty-nine. Hopefully, the reason for the drop in complaints was directly attributable to the outreach efforts.³⁶ I also coordinated the creation of a model AIDS education project to be required as a condition of probation for anyone convicted of a misdemeanor drug or sex crime, assisted the Los Angeles County Bar Association in the creation of a volunteer lawyer referral service for people with HIV, and participated in a City Attorney Crimes of Hate Task Force to deal with the rise in incidence of attacks on gay men.

In response to complaints that dentists were not accepting AIDS patients, I held a hearing that brought together leaders from the local dental professional associations, professors from the dental schools at UCLA and USC, and AIDS medical experts. We hammered out a consensus which led to the local professional associations creating a coalition committed to teaching dentists proper infection control techniques, combatting AIDS fears among dentists, and raising money for a local AIDS dental clinic.

Another case involved a man who worked in an accounting unit of a large Los Angeles medical center. A twelve year employee, he had recently returned from an AIDS-related medical leave of absence to face rumors flying about his work center regarding his condition. Nasty notes were left on his desk, telephones were sprayed with disinfectant, and he was shunned. I contacted the corporate counsel for the medical center and discovered that an AIDS education program had been initiated in the company but had not yet reached the accounting unit. Counsel agreed to schedule a session for this unit immediately and, the following week, the man reported that the atmosphere had been transformed. I later discovered that this man had been deeply involved in setting up a job fair for his local church parish and died the week before the fair began. However, he had finished all the organizing details and the fair was dedicated to his memory. A friend of his reported that without a doubt the extra few months of peace at work had enabled him to make this one last gesture of giving to others.

36. A similar analysis regarding San Francisco's drop in cases was offered by the San Francisco Human Rights Commission. See 3 AIDS, POLICY & LAW (February 24, 1988) at 8.

Comparing cases and strategies, my colleagues in New York and San Francisco and I agree upon several common themes. We had each observed how useful our laws³⁷ were in stimulating interest in the community in learning about AIDS among many previously unaware,³⁸ if for no other good reason than the fear of breaking the law. We had also learned the critical importance of emphasizing early intervention and mediation of complaints.

AIDS discrimination complaints are particularly ill-suited to the adversarial process. The stress of litigation is unhealthy for everyone, but particularly for those infected with HIV, whose major lifestyle change must include a reduction in stress. Furthermore, people with AIDS often will not survive the time protracted litigation can take, even with expedited court procedures.³⁹

The negotiating posture of AIDS discrimination cases is also different from other discrimination cases. AIDS discrimination complainants in the typical employment-related case are often prepared to settle if their health coverage is guaranteed, whereas others are prepared to wait until a full cash settlement for all damages is reached, for most HIV-infected people will become too sick to support themselves until a full settlement is reached and may not survive at all. Furthermore, HIV-infected people often cannot risk the further stigma and discrimination to which litigation threatens to expose them, even with the confi-

37. Which, in the case of New York City, was a municipal ordinance prohibiting physical handicap discrimination interpreted to include AIDS, rather than an AIDS-specific statute.

38. And with that point in mind, entitled the paper we presented at the Third International Conference on AIDS in Washington, D.C., *Municipal AIDS Discrimination Laws as Public Health Education Tools for Preventing HIV Transmission*.

39. For example, John Chadbourne, the real party in interest in the landmark California employment case of *DFEH v. Raytheon*, *supra*, note 19, died in January, 1985, twenty-five months before the Commission issued its ruling that AIDS was a covered handicap under California law. While this dramatically demonstrates the general incompatibility of the litigation process with the needs of people with AIDS, impact litigation — litigation which clarifies disputed points of law — is nonetheless essential in the battle against AIDS discrimination. Recent cases such as *Chadbourne, id.*, *Chalk and Thomas*, *supra* at note 23, have been critical in strengthening the negotiating posture of AIDS discrimination plaintiffs. Furthermore, Mr. Chadbourne knew full well that he might not live to see his case resolved, but believed that his fight to establish the legal rights of people with AIDS added meaning and value to his life. But most cases are not impact litigation cases, and plaintiffs must face the harsh realities of protracted litigation. For an excellent discussion of alternative strategies for resolving AIDS disputes, see Stein, *Strategies for Dealing with AIDS Disputes in the Workplace*, *THE ARBITRATION JOURNAL* (September 1987) at 21.

dentiality safeguards available to litigants.⁴⁰

AIDS discrimination suits also risk creating adverse public reactions, since they involve issues which are anxiety-provoking. For example, there was a great deal of backlash, confusion and polarization of opinion following The Justice Department memorandum issued in June 1986⁴¹ holding that discriminatory actions based upon irrational fears of contagion were not prohibited by the Federal Rehabilitation Act of 1973. That opinion was issued in response to a Department of Health and Human Services request for guidance on the applicability of federal law in that regard. Similarly, the *Markowski* blood-selling case⁴² and the *Jasperson* nail salon case⁴³ raised a great deal of consternation, even as both suits sought to establish important rights.

Moreover, the employment protection provision of California's municipal ordinances are extremely vulnerable to challenges asserting that they are pre-empted by state law.⁴⁴ Plaintiffs' attorneys proceeding under these provisions face the risk that a procedural ruling sustaining a pre-emption challenge would be misinterpreted by the public as a substantive ruling on the merits of such protections, further compounding the public's confusion and mistrust of public authorities regarding AIDS (a confusion and mistrust regularly manipulated by some who claim concern about AIDS⁴⁵).

40. Marjorie Rushforth, lead attorney in *Chalk supra* at note 23, revealed at the AIDS and law panel discussed *infra* at note 53, that within two hours after she filed John Doe papers in the case, an *Orange County Register* reporter had determined the name of her client by an analysis of facts which had to be alleged in the complaint. It was not too difficult to find out which male special education teacher in the Orange County school district had just returned from a medical leave of absence.

41. Office of Legal Counsel, U.S. Department of Justice, Memorandum for Ronald E. Robertson, General Counsel, Department of Health and Human Services, Re: Application of Section 504 of the Rehabilitation Act to Persons with AIDS, AIDS-Related Complex, or Infection with the AIDS Virus. The position of the Department was generally repudiated by the U.S. Supreme Court the following March in the *Arline* case, *supra* at note 23.

42. See *infra*, section III.

43. *Jasperson v. Jessica's*, No. WEC 10966 (Sup. Ct., L.A. Cnty. filed Mar. 23, 1988) (order denying permanent injunction).

44. See, e.g., Los Angeles City Attorney Report No. R-85-0711 at 1, 2 (Aug. 13, 1985); Letter from Legislative Counsel of California to Assembly member Art Agnos (Nov. 7, 1985); and Letter from the Attorney General's Office, California Dept. of Justice to State Senator Bill Lockyer (May 2, 1986).

45. Cf., e.g., G. ANTONIO, *THE AIDS COVER-UP?* (1986) and Scott, *Playing Politics with Death: Radical Homosexuals and the AIDS Epidemic*, *PASSPORT MAGAZINE* at 2 (June 1985) (published by Calvary Chapel of West China, CA).

Finally, the opportunity for litigation is further curtailed for government offices, since their enforcement powers are limited to filing injunctive relief actions.⁴⁶ Such actions not only require a higher burden of proof than an action for damages. They also require a fact situation suitable to an order for injunctive relief, an order often made unnecessary through negotiation, and in the case of personal services, thought by some⁴⁷ to be insupportable as a matter of law.

These problems are no secret to defense attorneys in AIDS discrimination cases. They are, however, the other major reasons, aside from the success of early intervention and mediation, why AIDS discrimination cases rarely go to court.

But defense attorneys fully taking the range of tactical truths about AIDS cases into account, can integrate competent representation with compassionate understanding. For example, a twenty-seven year old woman with a degenerative neurological condition could no longer live on her own despite regular visits from a social worker and a home health aide. The intermediate care facility which had accepted her for placement refused to admit her when it learned she was HIV-infected. The bruise on the woman's head from a fall she had suffered attested to the need for a rapid resolution to her problem.

When she filed a complaint with the City Attorney's Office, I quickly investigated the matter and contacted the facility's attorney. This attorney was thoroughly familiar with AIDS legal issues and could have advised his client to contest the matter as a defense tactic so that the woman could have won the legal battle and lost her war to find a safe environment quickly. Instead, this practitioner aggressively educated his client about the legal duties involved, the practical measures to be taken to implement HIV-related procedures, and arranged placement for the woman in a matter of days.

D. Conclusions and Recommendations

1. Policymakers must take into account the unique strategic aspects of AIDS discrimination cases, and fashion appropriate remedies

46. Cf., e.g., Los Angeles Municipal Code section 45.90(B)(2).

47. For example, the court in *Jasperson*, *supra* at note 43, wherein Judge Waddington denied the plaintiff's request for an injunction prohibiting the defendant from refusing him service, in part, because the court refused to "[C]ommand defendant to administer a pedicure, and, if she refused, subject her to incarceration until she complied." *id.* at 8.

emphasizing alternative dispute resolution. For example, hospitals should offer binding arbitration to HIV-infected patients to resolve promptly breaches in confidentiality which might quickly mushroom into a discrimination case.

2. AIDS discrimination laws with effective enforcement mechanisms are vital at all three levels of government — federal, state and local. It is an extremely useful negotiating tool for local government attorneys to have powerful state and federal investigative agencies backing them up, particularly when they can indicate in good faith that these agencies are prepared to accept locally negotiated settlements as settlements in full of potential state and federal claims. But sometimes, only highly flexible, locally-based government units can intervene quickly and draw on local relationships of mutual trust and respect to insure successful rapid resolution of AIDS discrimination cases.

3. AIDS discrimination legislation at the state and federal level must contain language which ensures that local laws are not voided on pre-emption grounds. Otherwise, courts may hold that state or federal regulations so thoroughly occupy the field of AIDS discrimination that local jurisdictions may not also regulate the area.

4. Government AIDS discrimination units must firmly commit to community outreach education programs which can prevent AIDS discrimination cases from occurring in the first place.

5. Local government attorneys must draw on local trust relationships to carry AIDS education programs to segments of the community otherwise resistant to such information.

6. Impact litigation is essential in strategically appropriate cases to establish needed case law and send a message to those in the community who would not otherwise comply with applicable legal standards.

III. Recalcitrant Individuals

It is beyond the scope of this Article to examine thoroughly the issue of "recalcitrants," those HIV-infected individuals who put others at an unreasonable risk of infection. However, a brief examination of the dynamics surrounding a highly-publicized case in California illuminates the complexities of this issue.

In June 1987, Joseph Markowski was arrested while attempting to sell his HIV-infected blood to a plasma center and was charged with

attempted-murder by the District Attorney.⁴⁸ Ironically, several months before, AIDS activists had brought intense pressure to bear on the California Association of Local Health Officers when they learned that the organization was reviewing draft guidelines regarding recalcitrants.

California law, as well as many other jurisdictions, assigns virtual absolute authority to public health officers regarding control of recalcitrants. However, these statutes had rarely been used since the nineteen twenties, and the California association wanted to develop internal guidelines to ensure a uniform response throughout the state. The activists opposed this process on the basis that it was immoral to devote resources to a negligible factor in the spread of AIDS at a time when many more effective public health educational measures had yet to be implemented.

Markowski changed the position of many of the activists in a hurry. Upon seeing the frightened public response to the case, they soon argued that such matters should be handled confidentially by public health officials rather than prosecutors. Prior to *Markowski*, these activists had failed to recognize that the government's duty to act varies radically, depending on whether people are merely sick or present a threat to others.

One of government's most fundamental functions is the preservation of public order. Definition of that order is open to debate. But the vision of a man, no matter how helpless and desperate, selling AIDS-infected blood to a plasma center, no matter what the heat processing procedures of the center might be, carried the sort of primal sense of threat which must be accounted for in any AIDS analysis.

Andrew Moss, an epidemiologist at the University of California, San Francisco, acknowledged the need for this accounting at a conference on AIDS co-sponsored by UCSF and the Society for Health and Human Values.⁴⁹ Dr. Moss stated that the San Francisco Public Health Officer's delay in making his decision about San Francisco's bathhouses damaged the public's trust in the willingness of officials to

48. On December 1, 1987, the attempted murder charges against Markowski were dismissed by Los Angeles Superior Court Judge Ron Coen, who held that prosecutors had failed to show that he had intended to kill anyone when he sold his plasma. Instead, Coen said, "The defendant's . . . intent was . . . to make enough money to support himself." Harris, *Changes Dropped Against Donor of AIDS-tainted Blood*, UPI (Dec. 2, 1987 at 1) (NEXIS). On March 2, 1988, a jury acquitted Markowski of the remaining charges of attempted poisoning.

49. "AIDS and the Medical Humanities," April 10-11, 1986.

act. Moss theorized that government inaction had created in the public's mind a perception of a leadership vacuum, a perception creating intolerable conditions of fear for the public.

Yet, the criminal justice system is a poor place for dealing with public health matters. It is adversarial and, in matters of HIV transmission, requires evidence-gathering intrusions into intimate matters. The issues involved in charging someone criminally with recalcitrant behavior regarding the virus' spread sets us apart, one against another, concerning a social crisis which requires communal responses. In dealing with recalcitrants, society must, amidst the other demands of the epidemic, find ways to do so which address the legitimate need for a sense of safety without furthering polarizing the community.

IV. HIV, Mental Disabilities and Civil Liberties

Our ambivalences and fears about the mentally ill have never been resolved. Yet HIV-demented people will vastly swell the ranks of the mentally ill. The vision of mentally ill people infectious for a deadly disease could lead to a deterioration in public attitudes towards all people with mental illness. This is particularly likely if hysteria explodes because the public first learns of the overwhelming implications of HIV neurological destruction from sensationalistic mass media coverage rather than from responsible public officials.⁵⁰

The numbers of HIV individuals requiring mental health care will rise in part because immunological treatment modalities are quite likely to improve, enabling individuals to live longer but in the process raising the likelihood of eventual mental impairment. These rise in numbers will also result from the likelihood that some number of those HIV-infected who are immunologically resistant will eventually go on to develop neurological difficulties. These rising numbers will further burden already straining mental health and chronic care facilities and raise vast problems in law regarding competency and intent.

The challenge this aspect of the epidemic poses can only be dimly perceived. One likelihood is the re-stigmatization of all who are men-

50. For instance, immediately after TIME and the ATLANTIC MONTHLY carried cover stories on AIDS and heterosexuals in February 1987, the waiting period at Los Angeles County's alternate test site mushroomed from ten days to eight weeks. For a thoughtful discussion about the role of the media in the epidemic, see Check, *Public Education on AIDS: Not Only the Media's Responsibility*, 15 HASTINGS CENTER REPORT 4 (Dec. 1985) (special supplement at 27).

tally ill once the public comes to associate some mentally disabled with infectiousness for a deadly disease. A second is the likelihood of the creation of separate and unequal institutional care facilities for those whose handicaps are non-HIV based and those who are demented or neurologically disabled and HIV-infectious. A third is an acceleration of the crisis in institutionally-based chronic care as more come to perceive the structural inadequacies of such institutions.⁵¹

HIV-demented individuals involuntarily committed to custodial facilities raise a chilling set of constitutional rights problems. Has the institution the right to test for presence of the virus without consent? How will others involuntarily committed into the same setting protect themselves from infection? What level of due process rights should be available to employees of these institutions as well as to those committed? How does the presence in these institutions of those committed because of recalcitrant behavior regarding spread of the virus affect these questions?⁵² And how can our answers to these questions abide by our fundamental constitutional commitment not to create separate and unequal facilities?⁵³

V. Fashioning an Education Program to Combat Discrimination⁵⁴

Teaching about the duties that we learn from the law can make learning the medical facts about AIDS easier. When we understand our duties to others regarding confidentiality and discrimination, we learn behavior which reinforces clear medical messages about AIDS. Our experience in Los Angeles helping to implement the City of Los Angeles' AIDS education program for its 33,000 employees has confirmed this.

Unlike most other AIDS education programs, ours has two goals. All programs seek to teach about preventing further spread of HIV. But the program mandated by the Los Angeles City Council on Octo-

51. See *infra* at section VI.

52. See *supra* at section III.

53. For a thoughtful analysis of these emerging problems, see panel discussion transcript, *AIDS and Civil Rights*, Whittier College School of Law Symposium, (March 4, 1988). (Transcript available from Whittier College School of Law, 5353 West Third Street, Los Angeles, CA 90020).

54. Taken from Schulman, *AIDS and Public Policy: Using Law Against Fear to Re-member Society*, (opinion piece), LOS ANGELES TIMES, March 13, 1988, part 5, p. 3.

ber 13, 1987 gained Surgeon General C. Everett Koop's praise because it also requires education about AIDS legal issues: how to ensure confidentiality in the workplace, prevent discrimination, and protect against liability.

The program began with special briefing sessions for elected officials and department heads to make sure there would be knowledgeable leadership. AIDS task forces are being created within each department to coordinate workplace education and problem-solving efforts. Each department has been ordered by the Council to accomplish three objectives: educate its employees; review and revise all policies and procedures in light of AIDS medical and legal information; and adapt daily department inter-actions with the community to further public education about AIDS. An illustration from the Department of Transportation provides a good example of the program's potential impact.

Drivers in city programs to transport the disabled learned in training sessions that it is illegal to refuse to transport people with HIV. Instead of merely being told that, however, with the resentment and misunderstanding that can create, everyone was taught why. No precautions are necessary to prevent the spread of AIDS in the normal course of transportation, since transmission requires infected blood or semen to have direct contact with another individual's blood system. Should a passenger bleed or vomit (which might contain blood), drivers were taught to clean up the mess or assist the passenger only after donning gloves to create a barrier against the virus entering through possible cuts or abrasions on the hands — and *always* to don the gloves.

The drivers learned what everyone must — that they need not know who has AIDS and who does not since their lawful and medically safe action should be the same in either case: use gloves to clean up all blood or vomit. Passengers who question the use of gloves learn accurate medical information about HIV transmission from the drivers. Gay men or intravenous drug users who might otherwise feel singled out will not since everyone receives similar treatment. The likelihood of HIV transmission in such a setting is tiny. But gloves are a reasonable response to just that tiny theoretical possibility some have urged as justification for more tyrannical measures against people with HIV. Everyone learns that protection of an individual's rights and the public's health adds up to the same thing — reason and fairness.

VI. The Threat of AIDS Euthanasia⁵⁵

A. Introduction

Perhaps the greatest form of discrimination is to feel dismembered, cut off from all hope. The impersonal nature of institutionally-based chronic care has already raised immense dilemmas in this regard for American society. Rather than feeling remembered as respected members of the human family, many individuals, often in concert with personal physicians, are quietly choosing to curtail treatments and end their lives rather than endure further pain and hardship from chronic illness and disease. Such decisions may be rational when viewed from the perspective of the individual. When viewed from a policy perspective, however, the conditions leading to such decisions warrant re-examination. When the mounting toll of the AIDS epidemic threatens to increase the numbers of such individuals many-fold, a continued unwillingness to consider altering the underlying conditions of such a problem amounts to a de facto policy of euthanasia.

Since the *Quinlan*⁵⁶ case first brought to the nation's attention in 1976 the profound issue of when we "pull the plug," remarkable changes have occurred in our attitudes towards death and in the balance of power between individuals and health care institutions. The holding in the 1986 *Bouvia*⁵⁷ case would have been unimaginable before *Quinlan* - that competent adults may refuse medical care even if doing so ends life. Yet the standard enunciated in *Bouvia* is emerging as a basic doctrine regarding the right to medical treatment.

Hospice has evolved since *Quinlan* as an alternative care philosophy for the terminally ill, offering humane care in the home made possible through the coordinated effort of interdisciplinary professional teams, family, friends and trained support volunteers. During this time, too, new legal devices like living wills and durable powers of attorney have also emerged, strengthening one's capacity to choose the kind of care desired.

While emerging legal standards, hospice, and durable powers of

55. See also, Schulman, *Stopping AIDS Euthanasia*, 2 TIKKUN 3 at 14 (July/August 1987) and Vrolyk *AIDS and Euthanasia: Is There a Morally Dubious Connection?*, BIOETHICS INSTITUTE NEWSLETTER (April 1988), Northridge (CA) Hospital Medical Center.

56. In the Matter of Karen Quinlan, 70 N.J. 10; 335 A.2d 647 (1976).

57. *Elizabeth Bouvia v. Superior Court of Los Angeles County*, 179 Cal. App. 3d 1127; 225 Cal. Rptr. 297 (1986).

attorney strengthen one's autonomy and control over the depersonalizing aspects of institutionally-based chronic care, other developments since *Quinlan* are altering the power relationships between individuals and institutions in ways that are not so benign. DRG's (diagnostically related groups), a new reimbursement scheme, assign lump sum payments based on the category of ailment rather than upon actual services rendered, creating incentives for physicians to mass produce medical care rather than tailor it to individuals' unique needs. Such new systems of health care delivery as pre-paid plans and health maintenance organizations also create institutional pressures upon physicians regarding individual care decisions.

These two recent developments, affirmation of one's right to refuse medical care and society's right to limit access to such care, create a potent mix in a time of epidemic.

B. *The Problem of Chronic Care*

The problem of chronic care has its root in the tremendous increase in acute care effectiveness in the twentieth century. That success has been marked by a phenomenal rise in the power and scope of medicine's capacity to overcome medical trauma. This power has stemmed from the efficiency of institutionalized professional care, coordinated with sophisticated technological advancements.

This rise in the power and scope of medicine, however, has altered the nature of morbidity. A century ago, and forever before, most individuals died rapidly of trauma or infection. The late twentieth century is the first era in which most will survive to die slowly from a new host of degenerative causes brought forth because of the survival rate from acute trauma made possible by medicine's power.

It is not surprising, then, to discover that America's early attempts to confront the new issues of chronic care would be modeled upon the success of acute care. In the mid-sixties, policy makers did just that in the decisions made regarding care of the elderly, choosing institutionally-based, professionally-dominated modes. Yet chronic care is not amenable to the institutionally-based combination of technique and management so successful in acute care settings. Chronic care requires a fundamentally different response, one grounded in the meaning and familiarity of community, family and friends.

One's broken leg needs to be set expertly and fast, and the patient may not suffer overmuch from brusque orthopedic surgeons and nurses waking him or her to take one's temperature every three hours. How-

ever, the dynamics of care for the chronically ill are far different. Altering senses of self, particularly of loss, must be addressed. In chronic illness, especially degenerative illness, mental, physical and emotional health interact in complex interweavings relating to senses of control, autonomy, dependence, involvement and the fear of abandonment.

C. The Dying Process, AIDS and Euthanasia

For those suffering irreversible, degenerative illness, all rationalizations about future benefit and present discomfort come to naught, means and ends come resoundingly together. It is not surprising, then, that the logical inconsistency of the acute care model and the chronic care condition should be felt most acutely by the dying. Institutional care, predicated necessarily upon the needs of institutions for procedures and rules, conflicts fundamentally with the needs of dying individuals for meaning now. This conflict when combined with AIDS creates the frightening preconditions for a policy of de facto euthanasia.

The HIV-infected are presenting massive new demands for medical and neurological chronic care. Those needing this care will be primarily gays and minority groups. The combination of the depersonalizing nature of institutionally-based chronic care, the right to refuse such care, the increasing scarcity for all of institutionally-based care resources because of the demands of the epidemic, and the socially unpopular nature of those creating the intense new demands upon such resources can scarcely not result in hostilities.

It is reasonable, in such an atmosphere, to consider that the HIV-infected will come to understand that it would be wise to exercise the right to refuse care. It need not be mandated. No legislation need even articulate such an unthinkable policy. But euthanasia can become a social reality, first for the HIV-infected, then for others who are institutionally bound, through a social unwillingness to develop other forms of health care services, ones which do not trample upon one's sense of personhood.

D. A Proposal for Home-Basing Chronic Health Care Services

Implementing home-based chronic care treatment programs requires both reorienting presently-existing health care institutions and altering the role of family, friends and volunteers in the process of care. Most health care institutions recognize the inherent dangers of the AIDS epidemic upon their fiscal and institutional stability. They fear

the overwhelming numbers HIV threatens. They fear the impact upon residency programs, and staff morale. They should welcome carefully coordinated efforts, then, to develop new methods of home care such as those being developed by San Francisco's gay community.

These efforts, to be properly stewarded, require the creation of a new national Commission on the Deinstitutionalization of Chronic Care. While it could be modeled after the commission on the abuse and neglect of children, its mandate should be broad, like the Marshall Plan or the Works Project Administration, for it must be capable of rationalizing the flow of federal dollars and the application of federal, state and local regulatory standards.

Incentives should be attached to federal dollars to require hospitals and out-patient facilities to combine home-based care with functions they continue to be suited best to deliver. Federal dollars allocated to home health agencies must mandate home health education as a central function of such agencies, enabling family and friends to learn the skills necessary to make possible extensive home care. Government must also encourage churches, synagogues, and other communities of faith to draw on the teachings of their traditions and help finance the mobilization and training of congregational and community volunteers to provide the routine yet vital support services necessary to enable family and friends to care for their own at home.

This approach on a massive scale does potentially change weekly patterns of life. Yet a new ethos of caretaking that redefined the nature of one's weekly chores—an hour or two as a home care volunteer, folding laundry or running errands, along with work, shopping and aerobic classes—could help regenerate the caring and communal values so badly needed today.

Such home care programs, however, must be coordinated through multi-focal, community-based facilities whenever possible. Since HIV has a disproportionate impact upon the inner-city poor, such programs would have a powerful effect. Inner-city based facilities coordinating home care programs which require as an essential component the education and involvement of family, friends and neighbors would powerfully reorient relationships by altering the oft-times destructive nature of institutionally-based services upon the poor.

For members of inner-city areas, the self-help and professional support created by such programs would transform their perceptions of the helping role of the professions. For care professionals, the paternalism inherent in institutionally-based care models which burdens professionals' self-esteem would be lessened. For middle class volunteers as-

sisting inner-city efforts, such programs offer the basis for strengthening religious and civic values.

This vision of care, however, cannot be only for those infected with HIV. Justice mandates that successful aspects of such programs be applied appropriately to issues of care regarding the frail elderly, those with Alzheimers, the neurologically-impaired, any who require chronic care. This would address a great secret in the health care world regarding AIDS, the fear that AIDS will overwhelm other health care programs, for good-hearted, long-committed workers in other health areas fight unseemly feelings of resentment and anger about the front page status of AIDS.

E. Conclusion

Most American religious institutions are centrally committed to relieving human suffering, yet many people feel dismembered from a religious sense of self. With AIDS as a catalyst, a new ethos of caring in our religious institutions could be constructed. That ethos would have to include all who were concerned, not merely the religiously involved. But it makes sense to begin with religious institutions because of their ideological commitments to human service, their pre-existing networks of potential volunteer labor and their low-overhead administrative structures. These factors make them a promising choice for an organizing base, coordinating with other community organizations and supported by government dollars, to slightly alter the nature of daily American life.

If society fails to consider these issues of care, then it risks creating for everyone, not merely those infected with HIV, de facto conditions of widespread euthanasia without even having to call it by its name. Enough is already known about the despair that sets in from the necessarily depersonalizing effects of intimate care from hired hands rather than from those who love us for ourselves. The choice to continue business as usual in planning to deliver HIV-related health care in institutional settings rather than at home will drive many, many people to choose to refuse care earlier than they might otherwise. We need not utter the word "euthanasia" in the legislature. We need not confess our underlying discomforts about most people infected with HIV, that they are gay, or drug users who are black or Hispanic. We need not say that we wish them dead. We need merely ignore what we already know.

In California, a proposed November 1988 ballot initiative would

legalize active euthanasia — the assented to killing of one person by another —for the first time in the United States. The proposal is hedged in by numerous safeguards. The organizers of the initiative originally told members of the Bioethics Committee of the Los Angeles County Bar Association that they expected the effort to enact their measure to take five years. That was eighteen months ago, in the Fall of 1986.

The Euthanasia Initiative speaks to people's unprecedented despair about the end of life. It is immoral in the same fashion that society's failure to confront the issue of chronic care is immoral—by seeming to leave individuals with no alternative to the indignities of their final days but to end them quickly. The challenge of AIDS is, ultimately, the challenge to find alternatives which do not permit that despair to transform all people from "us" to "them."