HIV Mental Health for the 21st Century

Winiarski, Mark G.

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Since 1981, when the first clinical descriptions of cancers and opportunistic infections associated with what is now known as the Acquired Immune Deficiency Syndrome (AIDS) were reported, the epidemic of the causative agent, the Human Immunodeficiency Virus (HIV), has spread substantially. With that epidemic, which has substantially affected public health, have come many changes: The epidemic's epidemiology has changed, governmental responses have evolved, and systems of health financing are being transformed.

These changes now challenge mental health providers and those in training for HIV/AIDS care in the next century. Above all, providers have learned that compassion is necessary but insufficient; mental health providers must be multifaceted in their skills, creative in their program development, politically aware, and involved in governmental policy-making processes that determine, through such issues as financing, what care clients receive.

The mental health lessons of the first fifteen years of the HIV/AIDS epidemic are conveyed eloquently in this book, meant to inform the next generation of providers. The authors of the chapters have practiced during times of great uncertainty, great tragedy, and great change. They have produced a body of knowledge — in clinical practice, development of new
model and programs of care, evaluation, and attention to public policy—that can be applied to mental health care generally.

To understand the context of the authors’ work, it will be useful to know the epidemic’s history as well as to understand its trends. This foreword notes some major issues that will confront HIV/AIDS mental health care in the next decade and suggests some responses.

*Why HIV/AIDS Programs?*

I first want to respond to several often-asked questions: Why are there special programs for people with HIV/AIDS? Are the programs justified? Are there compelling public health reasons for them?

The answer, in each case, is an unequivocal YES! HIV infection is lifelong. People at all stages can transmit the virus to sex partners or, in the case of pregnant women, to their children. This is not true for most forms of cancer, diabetes, Alzheimer’s disease, and other chronic conditions (although some have a genetic component). People do not look or act ill with HIV infection for most of the eight to fifteen years they are infected. Those with the virus and their sex or needle-sharing partners frequently don’t know about the infected person’s condition, thus limiting opportunities for safer behavior.

Women with HIV who receive zidovudine (ZDV, also known as AZT and Retrovir) during pregnancy and childbirth and who ensure that their newborns receive it are less likely to transmit the virus to their children. Because of reductions in levels of HIV in body fluids among those receiving mono or combination antiretroviral therapy, recently made easily demonstrable by viral load testing, people receiving these therapies may be less likely to transmit HIV to their sex partners as well. In addition, other infectious conditions associated with HIV, most notably tuberculosis and including multidrug resistant tuberculosis, present public health problems. Controlling HIV can reduce these conditions substantially.

Longevity and quality of life for those with HIV can be improved with adequate therapy. In addition, the substantial differences in health outcomes for people with HIV, depending on one’s gender or race/ethnicity, as reported in the literature, can be eliminated with expert care and good access to it.
Changes in the Epidemic’s Epidemiology

In the early to mid-1980s the estimated number of HIV-infected people increased sharply, but by the mid-1990s stabilized. Yet, the number of people who are severely ill and in need of substantially increased care continues to grow.

Cases of AIDS in the United States are now widely dispersed geographically after initially being concentrated primarily in large urban areas in states on the East and West coasts. This dispersal increases the need for expert HIV/AIDS care in the region between the coasts and in nonurban areas, a point discussed eloquently in chapter 10.

Nationally, HIV/AIDS is now the leading cause of death for persons aged 25–44 years. By June 1996, more than half a million (548,102) persons had been diagnosed with AIDS, and 62.5 percent of those diagnosed (343,000) had died. The federal Centers for Disease Control and Prevention (CDC) estimates that 650,000 to 900,000 people in the United States are currently infected with HIV. In the coming decade, hundreds of thousands of infected Americans will become ill, and many will eventually die of HIV-related illnesses. The total number of people developing late-stage HIV-related illnesses will be much larger for the next decade than for the one past, when the magnitude of the epidemic was just becoming defined. From July 1995 through June 1996, the most recent year of AIDS case reporting, 72,416 new cases were reported. If we assume that this will be the yearly average for the next decade, then it is likely that 50 percent more people will get AIDS during the next ten years than did so during the past ten.

Changes in Longevity Among Persons with AIDS

Not only will the next decade see more individuals diagnosed with AIDS, but persons with AIDS who have access to expert care will be living longer, with significant periods of severe medical problems.

This change in clinical outlook has occurred due to development and more aggressive use of improved but costly pharmacotherapeutic agents for prophylaxis and treatment of opportunistic infections; suppression of viral replication by combinations of antiviral drugs and the recently licensed protease inhibitors; and management of HIV- and treatment-related anemia, leukocytopenia, and immune suppression. Treatments now include those for opportunistic infections, antiretroviral agents, im-
mune system enhancers, and blood cell stimulators. More clients will be taking combinations of these drugs as more people at a late stage of illness are seen more frequently by providers.

The Public Health Service now recommends prophylaxis as well as secondary treatment for many opportunistic infections, antiretroviral therapy appropriate for state of illness and previous antiretroviral experience, universal HIV counseling and testing for pregnant women, and stage-appropriate counseling and access to the AIDS Clinical Trial Group (ACTG) 076 treatment regimen to reduce the risk of perinatal HIV transmission. Combination antiviral therapies including protease inhibitors, when appropriate, appear to suppress HIV in body fluids even more than antiretrovirals do as monotherapies. It is possible that the incidence of HIV transmission to sex partners will be reduced as viral loads in semen and other body fluids are diminished. As a result the dynamics of local epidemics could be altered.

**Demographic Changes Among AIDS Patients**

Demographic changes in the HIV/AIDS epidemic—increases in reported cases among women, children, orphan children, teenagers, injection drug users, homeless people, the chronically mentally ill, and minority populations—require changes in planning, organization and delivery of care for people and families with HIV.

Since early in the epidemic, national incidence rates of AIDS have been higher among African American and Latino populations than among whites, but the absolute numbers of those infected have always been larger in the white population, reflecting the epidemic among white gay men. In 1993 the absolute number of newly reported cases among minorities exceeded the number of newly reported cases among whites for the first time.

**HIV and Medically Underserved Populations**

Complicating the issue of demographic changes is the fact that a significant number of persons in the newly emerging groups are medically underserved, often because they lack health insurance, and many are victims of social stigmatization.

Many people with HIV or AIDS (11 to 31 percent in one study depending on stage) do not have health insurance. Others may not be
comfortable with Western health care or don’t know how to access a broad range of services. Some do not speak English, are mentally retarded or have significant learning disabilities, or have numerous survival needs that are major barriers to pursuing care.

In addition, many areas around the country have shortages of health care providers and, especially, of providers expert in the care of people with HIV/AIDS. Some providers may not wish to care for people with or at high risk for HIV/AIDS, such as injection drug or crack cocaine users, sex trade workers, homeless people, previously incarcerated people, and men who have sex with men. Other providers feel they don’t have the expertise to care for people with HIV. These factors have led to shortages of medical professionals in some of the areas hardest hit by the epidemic.

**Changes in the Federal Response to HIV Care and Prevention**

Initial direct federal investments in the care of people with HIV were exceedingly modest as the precise federal role in the epidemic was debated between the executive and legislative branches of government. Federal funding for care programs began in 1986 with $15 million for service demonstration grants to develop model systems of care for adults with HIV. In 1987 $30 million for pharmaceuticals assistance, principally for AZT, and $2 million for the first AIDS education training centers for health professional training were appropriated. In 1988 the Pediatrics and Family Demonstration Grants were begun. As late as 1989 only $60 million was appropriated for categorical HIV/AIDS care programs.

Federal contributions to epidemiology, surveillance, and laboratory research in the early and mid 1980s, while substantial, were thought by community advocates and many state and local government officials to be insufficient to the size of the growing problem. Clinical trials of antiretrovirals and drugs to treat HIV-associated infections began in the mid-1980s. Federal money was first made available for prevention programs in 1985 after HIV was established as the cause of AIDS. The money was to establish “alternate test sites” where people who wished to learn whether they had HIV could go for anonymous or confidential HIV testing and counseling rather than go to blood banks to donate blood so that they could learn their HIV infection status. During the next five years the CDC budget for HIV surveillance, seroprevalence studies, case reporting, counseling and testing, minority organization funding, school education
programs, prevention programs targeted to people engaging in high risk behavior, and funding of state and national public information campaigns and hotlines expanded significantly.

Unfortunately, federal prevention funding has not increased since 1990 and has never reached the levels required to bring multilevel HIV prevention programs to all communities in the United States. Prevention funding, including funds for adequate substance abuse treatment facilities and treatment “slots” for substance abusers who are not currently in treatment, continues to be small compared to the size of the problem. This has resulted in far less than adequate changes in HIV risk behaviors in critical segments of the population and slow or ineffective control of HIV transmission in many communities.

We now do know how to target interventions to specific populations, reducing the frequency of HIV-related risk behaviors and transmission. Condom use has been repeatedly shown in short-term studies to reduce or eliminate transmission. Many research-proven prevention interventions that result in lowered levels of risk behaviors have been developed and published, but none has been shown to eliminate risk behaviors for everyone over a long period.

Different interventions are required for gay men, adolescents, substance abusers, sex trade workers, heterosexual men and women, incarcerated people, serologically discordant couples, youth in school, hospital workers, and homeless people. Most approaches are labor-intensive and require at least several contacts between the prevention “intervenor/educator” and the individual or group participating in the intervention. Working proactively with and providing care for people who are already infected is an essential part of the strategy, as noted in chapter 8.

Different combinations of interventions are needed in different communities, targeted to locally important populations at high risk. These interventions can be school and street based. They can involve changing local laws to make syringes and other “works” legal to purchase and possess, setting up local hotlines, and instituting media educational efforts. The interventions must be carried out over a long period of time, with tolerance for slow success.

Prevention interventions should be planned and coordinated with CDC-funded planning bodies and Ryan White-funded community organizations. Providers of primary care in all settings, but especially in high-HIV-seroprevalence communities, should strongly encourage all adults and teens to know their HIV infection status for optimal medical management and prevention service provision.
Ryan White Comprehensive AIDS Resources Emergency (C.A.R.E.) Act

A national response that provides substantial resources to community organizations and other providers of outpatient health care and support services for people with HIV/AIDS is the Ryan White Comprehensive AIDS Resources Emergency (C.A.R.E.) Act. This first categorical HIV/AIDS care program was created in 1990 by the U.S. Congress because so many people with HIV, especially in urban areas, were unable to gain access to care and were filling hospitals and emergency rooms. Such people should have been treated elsewhere and should have been diagnosed and treated at early rather than late or terminal stages of illness. The Health Resources and Services Administration of the U.S. Public Health Service has administered the Ryan White C.A.R.E. Act.

By 1995, 15 percent of the cost of care for people at all stages of HIV infection was covered by C.A.R.E. Act funds. This legislation now provides more than $700 million to cities (Title I), states (Title II), and directly to service providers (Title IIIb, IV, and Special Projects of National Significance) for outpatient health care and support services. Spending priorities for these resources are determined by locally constituted planning councils (Title I), consortia (Title II), or groups of providers (Title IIIb, IV, and SPNS). The funds are more flexible than Medicaid funds and cover people not eligible for Medicaid and Medicare. They can be used for many HIV-related outpatient services that are not covered by some other payer.

Of critical importance is the fact that the funds can be used for necessary nonmedical services, to recruit and retain providers, and to deal with problems of daily life such as transportation, day/child care, home care, housing, and hospice care.

Equally important is the legislatively mandated process requiring local assessment of gaps in care, prioritization of the uses of the funds, and preparation of a plan for coordinated, comprehensive community services for diverse populations of people with HIV/AIDS. During the first five years of the Ryan White C.A.R.E. Act, an increasing number of planning councils of major urban areas elected to use some of their federal funds for mental health services, and the Special Projects of National Significance (SPNS) program, initially funded under Title II, has supported development of new models of mental health care, some of which are described in this book. From 1994 to 1998, SPNS funds were combined with funds from the federal Substance Abuse and Mental Health Services
Administration's Center for Mental Health Services and the National Institute of Mental Health to expand mental health demonstration projects for persons with HIV/AIDS.

The coordinated outpatient programs funded by the Ryan White C.A.R.E. Act have been successful in improving access to primary care, increasing availability of diverse types of services, substantially increasing the numbers and the diversity of underserved people in outpatient primary care, and keeping people out of inappropriate care in emergency rooms and acute care hospitals. Preliminary local evaluations indicate that making outpatient services more available and funding support services such as transportation, day care, home care, and hospice care have resulted in decreased emergency room use and decreased the frequency and reduced the duration of inpatient hospitalization. The resultant cost savings are available to support the costs of outpatient services that partially substitute for inpatient care.

Since 1994 the Community Planning Initiative, a process in many ways similar to the Ryan White planning council and consortia processes, has been supported by the CDC. Local and state planning bodies plan prevention programs and prioritize the use of CDC prevention funds. In some cases the same people serve on both Ryan White consortia or planning councils and the local or statewide prevention planning body; in other cases, the planning is more formally coordinated. These linkages are critical for implementation of federal initiatives such as the universal approach to HIV testing for pregnant women recommended by the Public Health Service and the linking of women with HIV to systems of care that can offer perinatal zidovudine therapy and long-term follow-up for the women and their children, regardless of the infection status of the infant.

**Political Advocacy**

Both of the national programs to use federal funds to plan and carry out locally responsive care and prevention programs came about because of political advocacy and the use of political power by the gay, minority, and other communities and a variety of local, regional, and national organizations working in coordination with public health and government advocates. The future of health programs targeted to specific medical conditions will depend on such organized advocacy and political action. Other efforts in political advocacy that have been at least partially
successful in obtaining federal support include end-stage renal disease, hemophilia, sickle cell disease, Alzheimer's disease, and breast cancer.

Growing Collaboration Between Government and Communities

During the early part of the HIV epidemic, local communities and community organizations, often from the gay community, made the most proactive and effective responses to the HIV epidemic. Prevention and care initiatives were supported by volunteers and local fund-raising. Later, local and state governments in some areas made major financial contributions to HIV prevention and care initiatives.

More communities will become involved with AIDS-related issues at school, in hospitals, in long-term care facilities, on sports teams, and in community service agencies. Mental health providers will need to play leadership roles in communities to help develop solutions based on scientific information, not on fear and myth.

Changes in HIV/AIDS Care Financing

Cost remains a significant barrier to care. The direct cost of health care for people with HIV/AIDS, from the time of infection to death, has been estimated to be approximately $119,000 per patient. This estimate was made before viral load testing and combination antiviral therapy became standards of care. The monthly costs of medical care for people with AIDS who meet the pre-1993 CDC case definition (they have Kaposi's Sarcoma or some HIV-related opportunistic infection or malignancy and are not diagnosed with AIDS only on the basis of lab findings of less than 200 T-helper cells, also called CD4 or CD4+ T lymphocytes), have been estimated in 1993 — before viral load testing and combination therapies — to be $2,764. These costs, however, rise steadily during the last six months of life to more than $8,000 during the last month of life, as determined in 1994. At earlier stages the monthly costs of medical care were estimated in 1993 to be $990 for people with variable severity of illness who have fewer than 200 T-helper cells, $430 for people with 200 to 500 T-helper cells, and $282 for asymptomatic people with more than 500 T-helper cells.

In the mid-1990s there is no comprehensive way to finance access to comprehensive care for all people with HIV/AIDS who do not have health insurance. Medicaid covers 40 percent of the costs of care and
therapies for people with HIV; however, this program covers some, but not all, people at late-stage illness. In addition, the financial eligibility criteria vary from one state to another, and the services covered and the levels of reimbursement to health care providers are diverse as well. To receive Medicare, one has to have been receiving Social Security disability benefits for twenty-four months, which, if one includes the five-month initial wait for those benefits, means a delay of twenty-nine months after a determination of an AIDS-related SSI disability has been made before Medicare kicks in. In other words, to get Medicare, a person with AIDS has to survive twenty-nine months after he or she is determined to be disabled. Other patients' care costs are covered by the departments of Defense and Veteran's Affairs.

**Medicaid Changes**

Changes in Medicaid funding and administration, including the possible institution of block grants to the states, will undoubtedly significantly change eligibility and services covered for eligible Medicaid recipients, thereby increasing the pressure on the use of Ryan White funds. Some states have already reduced Medicaid reimbursement rates for providers, and many are mandating delivery through managed-care programs.

**Managed Care**

Another major potential barrier to effective HIV/AIDS care, which includes mental health care, is the rapid movement of health care financing and service delivery systems into the diverse forms of managed care. Congressional and state action to cut spending on Medicaid and Medicare will move more clients with HIV into managed-care arrangements. Mental health service providers themselves may be part of several health plans or care networks; others may work at community organizations that bill insurers for the services provided to their clients.

Advocacy organizations and people with HIV/AIDS have expressed concern that traditional or evolving managed-care management practices will result in poorer quality of care and health outcomes for people with HIV/AIDS. These practices include allowing access only to “in-network” providers (patients can use only providers on a list provided by insurers; use of other providers results in reduced or no reimbursement of costs) or to salaried employees and facilities of the health maintenance organization.
(HMO); preapproval requirements for access to specialists and specialized therapies; preapproved but possibly limited pharmacy formularies; utilization review; capitation; profit sharing for providers; limited mental health and substance abuse treatment benefits; lack of social services; and limited or no access to clinical trials.

Many managed care organizations do provide expert comprehensive HIV care with or without the use of some or all of these management techniques. The AIDS Health Care Foundation, a capitated HIV care provider in Los Angeles, uses many of these techniques and still provides excellent care.

Mental health service providers will need to be advocates for their clients to help them obtain the services they need and to alter benefits packages as needed in order to offer optimal cost-effective care to their clients and their families.

**Carve-outs**

In some areas, HIV treatment and behavioral medicine (substance abuse treatment and mental health services) carve-outs are being developed in which managed-care clients receive specified services from a group of providers who specialize in those areas. Reimbursement may be fee for service or partially or fully capitated, with varying copayments and limits on visits or hospitalization for mental health and substance abuse treatment. It is likely that services such as behavioral medicine and care for special populations such as people with HIV, children with special health care needs or disabilities, and clients in need of rehabilitation services, will increasingly be carved out in high-population-density areas or in areas where these conditions are especially prevalent and where groups of capable and interested specialty providers are available. In rural and less population-dense areas or where conditions such as HIV are rare or of low prevalence, care will be provided by generalist physicians or regional specialists and will not be carved out.

A challenge for the future is to link service networks for people with HIV/AIDS in the private, increasingly managed sector with public-sector providers and community organizations that provide a variety of outpatient services and receive categorical federal or state subsidies or Medicaid reimbursement for the services. More comprehensive and cost-effective service networks might result.
What These Changes Mean to Mental Health Providers

The trends I have described mean that many more individuals and families all over the United States will need HIV/AIDS-related mental health services but will have to seek them in an increasingly complicated care environment.

With HIV/AIDS may come a great deal of psychological suffering, including feelings of great loss and existential terror and psychiatric conditions such as depression and mania, and neurological problems, including AIDS Dementia Complex. But the role of HIV/AIDS-related mental health providers must extend way beyond coping with those issues. As people live longer with major medical, social, and health systems management problems, mental health practitioners will play an increasingly central role in their care. They will have to become broad experts on HIV/AIDS care and in advocacy.

- Clinicians will have to assist people who live in high-prevalence areas and those engaging in high-risk behaviors to learn their HIV status and must educate those infected regarding access to expert primary and specialty care. To do so, mental health providers will need to know about the local availability of specific services. They should know the local HIV-knowledgeable primary care physicians, the providers of social services, specialists in treatment during pregnancy for women with HIV infection, the hospitals prepared for providing zidovudine during delivery, and what follow-up services are available for mothers and their infected and uninfected babies. They will also need to know something about the side effects of the increasing armamentarium of HIV-related drugs both alone or in combination, since some medications have psychiatric side effects.

- Clients' depressions, anxieties, fears, and anger, their frustrations with systems of care, and many other issues will challenge the mental health provider. In many cases, family therapy, couples counseling, and/or individual mental health therapy to patients with HIV as well as to members of the nuclear and extended families will be needed. As noted by Dottie Ward-Wimmer in chapter 12 on work with children, many families include more than one person infected with HIV.

- Comprehensive, organized systems composed of linked community providers who regularly meet to solve referral and joint care
problems will be needed to facilitate the substitution of outpatient services for inpatient care. Because mental health providers, including case managers, may best know the patient’s entire “system” of care, they will have to be present at those joint meetings. Much of the coordination of client services may become the responsibility of mental health service providers.

- Mental health providers who wish to work with underserved groups will need special, culturally based training. Learning how to talk with people using their own language, to build relationships with them that are based on respect, and to provide assistance in locations where they are comfortable coming for care is part of the process. Mental health professionals likely will have to spend more time with outreach workers who are members of the subculture, learning the local places where underserved groups spend time and serving them in those locations.

- To reach and keep people in HIV/AIDS care, organizations will have to provide comprehensive social services, including housing assistance, substance abuse treatment, child care and adult day care, mental health services, transportation, and emergency financial support. Services for women, children, and adult male family members may most effectively be located in the same facility so that different family members can make appointments to receive services at the same time and place. Services may have to be located in nontraditional places such as congregate living facilities, substance abuse treatment centers, homeless shelters, “storefront” operations, and mobile vans.

- New uses of technology may partially substitute for costly or logistically difficult office, hospital, or laboratory visits. Home computers, video communication, and twenty-four-hour hotlines may reassure clients and families and improve care. Mental health providers should be significantly involved in this response.

- Mental health service providers may need to be advocates for their clients to help them obtain the services they need and to alter benefits packages as needed so that their clients and their families receive optimal cost-effective care.

- As HIV/AIDS becomes more visible in communities that have not yet been significantly affected, such as suburbia, mental health practitioners must assist all to find realistic and compassionate approaches to their epidemic.
Conclusion

The HIV epidemic and the resulting large numbers of people with AIDS are having a substantial impact on the public health of the United States, on the practice of medicine, and on mental health services. Within the epidemic, major changes are taking place in the types of clients and families with HIV/AIDS to be served, the diversity and the growing effectiveness of medical therapies, clients’ longevity at later stages of infection, the types of services provided, settings for care, the organization of care systems, and the financing of care.

These changes will dramatically impact mental health providers in the upcoming decades. This book, which is about successful mental health service delivery to those affected by HIV/AIDS, presents creative and proven ideas and systems of care that can be adapted to individual and local circumstances.

The models of care described in this book emphasize at their common core a systems approach to HIV care. Comprehensive care that is planned and implemented by a partnership of all communities affected — clients, their families, providers, institutions and agencies, and others in the community — has been shown to be effective.

The contributors to this volume believe that care and prevention programs that use community resources for the betterment of all can make a transforming difference in the lives of clients and families, for the providers and for communities. Clients can be more satisfied with their care, can live and be more productive longer, and can avoid much costly emergency room and acute hospital care. Communities can more compassionately and cost-effectively live with the local reality of HIV. The authors hope that this book will contribute to improving the lives of people with HIV everywhere as much as working with people with HIV/AIDS has transformed our own.