HIV/AIDS AND LONG-TERM CARE: A STATE PERSPECTIVE

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ABSTRACT Long-term care services for people with human immunodeficiency virus/acquired immunodeficiency syndrome (HIV/AIDS) were fostered in New York State by passage of HIV-specific regulations that set program standards and authorized reimbursement rates sufficient to support these standards. A rapid expansion of HIV-specific capacity has occurred. Demographic and selected clinical characteristics of the populations in AIDS residential health care facilities and AIDS adult day health care programs in New York State are presented. Aspects of the service models for these two program types that have changed to meet new needs are discussed.

INTRODUCTION

The New York State Department of Health (DOH) AIDS Institute was established by legislative mandate in August 1983 to coordinate New York's response to the emerging human immunodeficiency virus (HIV) epidemic. Initially, the development of health care services for people living with HIV/AIDS (acquired immunodeficiency syndrome) focused on ambulatory and acute care services. The development of a health care infrastructure for HIV care in New York State was aided by the establishment of enhanced Medicaid reimbursement rates for HIV care to assist program development and to reflect the high costs of providing care.

Subsequently, the DOH AIDS Institute supported the development of HIV-specific long-term care programs. A large capacity needed to be developed, and the traditional geriatric long-term care programs did not offer these services immediately. Therefore, the DOH AIDS Institute supported the development of

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new facilities that would specialize in providing services to people with HIV/AIDS. Incentives were established to attract providers, and a rate methodology was developed that recognized the increased costs of providing services to this population and was sufficient to support program development.

The continuum of long-term care services specific to people with HIV/AIDS in New York State includes AIDS adult day health care (ADHC) programs, AIDS home care, AIDS residential health care facilities (RHCs), and AIDS hospice. This paper focuses on the characteristics of patients in AIDS RHCs and AIDS ADHC programs as these two models of long-term care differ most significantly from traditional geriatric long-term care services. Changes that have occurred in these models, based on changing needs of the participants, are described.

The Chronic Care Services Section was established within the AIDS Institute's Division of HIV Health Care in 1989 to oversee program development and to provide quality oversight. This Section established program standards, including strong social and supportive service components, to ensure that HIV long-term care programs met the needs of people with HIV/AIDS. This Section worked with health care and community-based providers to develop capacity within a continuum of HIV-specific long-term services.

It was recognized that people with HIV infection who required long-term care services differed significantly from the geriatric population in long-term care. Many people with HIV are young, of racial or ethnic minorities, more likely to have a history of substance abuse, and have major psychiatric disorders. A significant proportion does not have social support systems that can assist in the care of their chronic medical and functional needs. It was clear that models of long-term care service provision would need to be altered to reflect these different service needs. It was especially important to include case management services, substance use treatment modalities, and mental health services in these programs. Because of a limited number of approved treatments for HIV and associated infections at that point in the epidemic, it was necessary to ensure access to clinical trials.

DATA SOURCES

Epidemiologic data cited are from the New York State Department of Health Bureau of HIV/AIDS Epidemiology and the Centers for Disease Control and Prevention.

The Minimum Data Set (MDS+) is the only comprehensive source of demographic, clinical, and functional status information for all residents of the residential health care facilities. Typically, it is completed by trained RHC nursing staff

for all patients on admission, discharge, and quarterly, and also when there is a major change in clinical status. The MDS+ is not HIV specific, and a less comprehensive source has been utilized to provide additional HIV-related clinical information. Also cited are data from 1998 published by Greenberg et al.,¹ who surveyed a sample of 111 residents in the 12 New York City AIDS RHCs for selected demographic, clinical, social, and laboratory data.

There is no equivalent of the MDS+ for registrants in the AIDS ADHC programs. Clinical information is available from a survey of 80 registrant charts from four programs conducted by the AIDS Day Services Association.

AIDS RESIDENTIAL HEALTH CARE FACILITIES

In the early 1980s, people with AIDS requiring nursing facility care were often unable to obtain placement in "mainstream" RHCs (as they are termed in New York State) and died after lengthy hospitalizations. Although placement in mainstream RHCs was difficult because of the expectation of the RHCs that the cost of providing AIDS residential long-term care would be higher than available reimbursement,² the anxiety about response of their staff, residents, and the families of residents was a significant factor.³ The difficulty in effecting placement for people with HIV/AIDS who required residential health care was a prime reason that these HIV-specific programs were developed.

AIDS RHCs were established in New York State by regulation in 1988. In areas of New York State with high seroprevalence, the establishment of discrete AIDS facilities, and of separate AIDS units within larger RHCs, was encouraged. These facilities were expected to provide residents with an array of medical, nursing, substance use, nutritional, recreational, case management, and risk-reduction services. In areas of the state without a demonstrated need for discrete AIDS facilities or units, existing facilities were encouraged to revise their licenses to include AIDS "scatter beds."

New York State promoted the development of these specialized RHCs by providing low-interest loans for such activities as preparation of certificate of need (CON) applications and preliminary architectural plans. These funds were particularly important to organizations that were not experienced health care providers. These nontraditional sponsors, organizations with a commitment to HIV services that previously had provided housing, drug treatment services, and community social work services, were now expanding to offer health services. The AIDS Institute provided these agencies with technical assistance so that they could offer health care services in compliance with state regulations and codes.

An incentive for providing services to people with HIV infection was that facilities with AIDS-specific units were able to access enhanced Medicaid rates. The usual tool used to calculate resource utilization for residents in nursing facilities (Resource Utilization Group Score) was adjusted to reflect real costs of HIV care that were not captured in this assessment. In addition, there was a 20% increase in indirect costs and increases to cover increased medical and substance abuse services, pharmacy costs, and a capital component. Facilities that had residents in AIDS scatter beds received additional reimbursement based on the adjustment to the Resource Utilization Group Score. The numbers and costs of HIV treatments rose more quickly than rates could be reconfigured, and eventually many HIV drugs for residents in AIDS facilities and scatter beds were authorized to be billed directly to Medicaid.

Modifications were made to the traditional geriatric nursing home model to meet the needs of this relatively nontraditional patient population. Three types of facilities were developed: institutions offering highly skilled care for functionally dependent people with multiple nursing or rehabilitative needs; institutions for a more ambulatory population requiring frequent medical supervision, as well as ancillary services; and institutions more closely resembling a drug treatment therapeutic community.

A needs methodology established a target number of RHCF beds that this population would require. The AIDS Institute strongly encouraged the development of sufficient capacity. Once the program standard and reimbursement regulations were promulgated, providers submitted CON applications and the state approved them, and a rapid growth in the number of beds in discrete AIDS units occurred. Perhaps reflecting changes in the chronicity of needs of people with AIDS, the growth in available HIV-specific long-term care beds mirrors the rise in the number of people living with HIV more closely than changes in the number of incident cases of AIDS (Table I).

In addition to these beds, there are 200 beds in a New York City chronic care hospital that provides similar services, for a total of nearly 1,300 beds in 1998.

All of the AIDS RHCFs in New York State provide medical services via a closed-staff model; physicians are salaried full- or part-time employees of the facility. The standards of the program encouraged an enriched physician-to-resident ratio of 1:40 and required that a physician always be on call or on site in the RHCF. Unlike the fee-for-service model that exists in most other RHCFs, this method of providing physician services does not limit the number of visits a resident can receive.

TABLE I AIDS Residential Health Care Facility Beds and AIDS Cases Over Time

Year	Total Available Beds*	Total AIDS Cases Alive†	New AIDS Cases†
1989	156	11,000	8,029
1990	222	14,000	8,971
1991	441	16,500	10,687
1992	481	21,000	12,966
1993	529	27,000	14,999
1994	828	32,000	14,275
1995	1142	35,000	13,335
1996	1076	37,000	10,401
1997	1076	44,500	8,309
1998	1076	50,179	5,558

*From NYSDOH/AI Chronic Care.

†From NYSDOH Bureau of HIV/AIDS Epidemiology: 1998 incomplete.

CHARACTERISTICS OF RESIDENTS IN AIDS RESIDENTIAL HEALTH CARE FACILITIES

The demographic characteristics of people with AIDS in New York State have changed significantly, similar to, and perhaps several years in advance of, the changes in AIDS demographics nationwide. A greater proportion of newly diagnosed AIDS cases in New York in 1998 occurred among intravenous drug users and in African-Americans and people of Hispanic origin than in national statistics. In addition, a higher proportion of cases occurred among women in New York State than nationally. The demographics of residents of the AIDS RHCFs in New York State differ from statewide AIDS figures. Residents in the AIDS RHCFs in New York State are even more likely to be African-American or of Hispanic origin, and an even higher proportion are women than are New York AIDS cases in general (Table II).

Clinical data from a sample of 111 residents at 12 RHCFs in 1998 reveal a relatively advanced level of immunosuppression and a lack of viral suppression, but both improved somewhat after admission. Just over 50% received highly active antiretroviral therapy (HAART), a regimen comprised of two nucleoside reverse transcriptase inhibitors and a protease inhibitor or non-nucleoside reverse transcriptase inhibitor, prior to admission to the RHCF; a majority received HAART once admitted. Many residents had laboratory evidence of hepatic disease. Past and recent illicit drug use was high (Table III).

While the traditional method of estimating resident resource utilization in the

TABLE II Demographics of All AIDS Cases and Residents of AIDS Residential Health Care Facilities (RHCF)

	Cumulative US AIDS Cases,* %	1998 NYS AIDS Cases,† %	1997 NYS RHCF AIDS Cases,‡ %
Men who have sex with men	47.8	29.2	8.1
Intravenous drug users	23.3	51.7	56.8
Heterosexuals	9.4	10.2	26.1
Race/ethnicity			
White	44.6	21.1	9.0
African-American	36.2	44.6	60.4
Hispanic	18.1	29.6	30.6
Gender			
Male	83.8	73.4	57.7
Female	16.2	29.4	42.3

*From CDC.

†From NYSDOH Bureau of HIV/AIDS Epidemiology.

‡From MDS+.

RHCF is based on functional impairment, this is of limited usefulness in the AIDS RHCFs. Data from the MDS+ indicate that on admission, 57% of residents were activity of daily living (ADL) independent, 24% had limited ADL dependency, and only 19% had high degrees of ADL dependency. However, more

TABLE III Selected Characteristics of Residents of New York AIDS Residential Health Care Facilities, 1998 (N = 111)

Laboratory	
Viral load (median log ₁₀) on admission	4.56
Viral load (median log ₁₀) most recent	3.75
CD4/mm ³ on admission	132
CD4/mm ³ most recent	181
Hepatitis B surface antigen positive, %	22
Hepatitis C antibody positive, %	52
Drug use, %	
History crack use	51
Recent crack use	24
History intravenous heroin use	54
Recent intravenous heroin use	21
HIV treatment, %	
On HAART	80
Protease inhibitor experienced prior to admission	55

Source: From ref. 1.

than half had dementia by the end of their stay, and a significant percentage required skilled services such as intramuscular or intravenous medications.

AIDS ADULT DAY HEALTH CARE

In 1993, regulations were promulgated that set program standards and reimbursement rates for AIDS ADHC. These programs were intended to serve a medically fragile population at high risk of nursing home placement. Medical eligibility for these programs was established as requiring a diagnosis of AIDS or symptomatic HIV disease. ADHC provides multiple services at one site, as well as a therapeutic milieu, for people who benefit from a structured community setting. A minimum of 3 hours per week of health services must be provided to each registrant, who is required to remain at the program for at least 3 hours per visit. A wide array of services is offered, including medical care and nursing, case management, substance use, mental health, and nutritional services. In general, the ADHC programs do not provide full HIV primary care to participants, but function as an extension of the primary care provider. In addition, the ADHC programs provide intensive adherence services to help registrants maintain their complex medication regimens.

Grants from New York State and Ryan White CARE Act Title I funds were provided to agencies to support developmental activities to prepare for submission of a CON. While a few ADHC programs were sponsored by traditional health care institutions, most were sponsored by community-based organizations. Many of these agencies did not have extensive experience in providing licensed health services. The AIDS Institute provided significant technical assistance to foster development of management systems and clinical services.

The overall capacity of the AIDS ADHC programs grew from 50 daily slots prior to the establishment of the AIDS-specific day health care reimbursement of \$150–\$160 per day to 286 daily slots in 1996, and a total of 726 daily slots were open by 1998. Registrants in these programs generally attend 2 or 3 times per week, with approximately 1,500 total registrants enrolled to maintain a daily census of 726.

A survey by the AIDS Day Services Association (unpublished data) of demographic and clinical characteristics of a sample of 80 participants in selected ADHC programs in 1998 demonstrated frequent substance use and high utilization of substance use treatment modalities. A very high percentage had a serious psychiatric diagnosis (Table IV). This same survey noted that 25% of registrants had a history of abuse or neglect, and 12% were on parole from the criminal justice system. While 99% of registrants were independent in ADL, 25% needed

TABLE IV Characteristics of Registrants in Adult Day Health Care in New York State, 1998 (N = 80)

	%
Substance use	
Alcohol use to intoxication	32
History of intravenous heroin use	55
History of cocaine use	72
History inpatient rehabilitation	25
History inpatient alcohol/ drug detoxification	39
Mental health	
In psychiatric care outside ADHP	32
History of psychiatric hospitalization	71
History of major depression	42
Diagnosis of schizophrenia	7
Anxiety disorder	36
Adjustment disorder	24
Dementia	14

Source: ADSA, 1998.

help with medications, and 28% needed help making or keeping medical appointments.

OBSERVATIONS AND LESSONS LEARNED

The AIDS RHCs and the AIDS ADHC programs continue to provide important services to people in New York State living with HIV/AIDS who require long-term care services. The past 10 years of providing such services permits some observations regarding these two AIDS/HIV long-term care program models and how they have changed as the needs of people living with HIV/AIDS have changed.

AIDS RESIDENTIAL HEALTH CARE FACILITIES

First, physician services in the AIDS RHCs have been organized via a closed-staff model, with the per diem reimbursement enhanced to cover these personnel costs. The AIDS RHCs have had stable, skilled physician services. This model may be replicated directly in other specialty nursing facilities⁴ and may foreshadow trends in RHC care in general in New York State.

The New York State Department of Health initiated a demonstration project in 1992 to identify the most cost-effective way to deliver primary care to residents in non-AIDS RHCs. At the time, primary care was provided by fee-for-service physicians in 80% of the RHCs in New York State. In a closed-staff model, 21

RHCFs were supported to hire physicians, nurse practitioners, and physician assistants.

An analysis of the results of this study found that patients, staff, and administrators reported greater satisfaction with this closed-staff model. Hospitalization rates declined for residents in these sites.⁵ While personnel costs were greater, this model of providing physician services was cost effective when decreased inpatient expenditures were factored in. Unlike the fee-for-service model, physician visits are not capped in the closed-staff model, and there is no incentive to send residents to the hospital solely based on number of physician visits. Some hospitalizations may have been avoided by closer physician monitoring in the RHCF.

Second, direct billing of HIV medications to the Medicaid program has ensured wide access to antiretroviral treatments. Originally, the medications that could be billed directly to the Medicaid program were limited to zidovudine, pentamidine, and ganciclovir, and nursing facilities were reluctant to cover the additional costs of expensive HIV drugs. As a result, some hospitalized patients were refused placement in nursing facilities. Approval was sought and obtained to allow all antiretroviral agents to be billed directly. Surveys demonstrate very high rates of utilization of standard-of-care antiretroviral therapy by residents in AIDS RHCFs.

Third, while hospitalization rates and length of stay for people with HIV have decreased, there has not been a matching decline in the number of people in the AIDS nursing facilities. The chronic care needs of people with HIV/AIDS continue. Many residents of AIDS RHCFs have multiple needs that cannot be served by community resources. Many residents are previous or recent substance users with a history of recent homelessness; a significant number have dementia or a thought disorder. Anecdotal reports from medical directors of the AIDS RHCFs indicate that the percentage of residents with dementia and major psychiatric disorders has increased dramatically. In addition to requiring intensive ongoing HIV clinical services, these residents have serious comorbidities relating to mental illness and substance abuse that are best addressed in a controlled residential care setting.

Fourth, an increasingly important service that the AIDS RHCFs provide to their residents is support for adherence to antiretroviral regimens. Many residents are resistant to the multiple antiretroviral agents utilized prior to admission due to poor adherence and are on salvage therapy, with limited further medication options if they become resistant to their current regimen. In the facilities, medications are administered by the nursing staff, and high levels of adherence can be ensured.

AIDS ADULT DAY HEALTH CARE

First, adherence services are an increasing component of ADHC. Due to declines in HIV-related morbidity and the number of people newly diagnosed with AIDS, there may be fewer people who meet the medical criteria for eligibility to ADHC (AIDS or symptomatic HIV illness). However, a large number of people who did not meet the original medical eligibility are unlikely to adhere for long periods to their HIV drug regimen without a formal structured program. Based on these observations, eligibility criteria were expanded in 1997 to permit enrollment of all HIV-infected persons receiving HAART who would benefit from adherence-related services.

While ADHC is unable to provide directly observed therapy for all doses, program nursing staff assist the registrant to set up weekly or daily medication parceling boxes and provide treatment education. The programs have been encouraged to use the comprehensive care planning process to identify impediments to adherence and include the entire multidisciplinary team in assisting the registrant to adhere to medication regimens.

Second, ADHC was planned originally to serve medically fragile HIV-infected persons who would attend for 4–6 months. Some registrants were expected to improve their medical status, learn sufficient life skills, and then return to ambulatory care. The severity of HIV illness was expected to advance in others, who would ultimately require RHC placement. However, a significant percentage of those in ADHC, though medically stable, benefit from ongoing participation in a structured program and may remain in the program long term. These programs remain important sources of care for registrants, who might deteriorate without the services of these programs.

Third, the ADHC programs require a minimum attendance of 3 hours per visit in a congregate setting, with full participation in a number of clinical services. Some HIV-infected people with multiple mental health, substance use, and adherence service needs do not tolerate highly structured programs. Medicaid will only reimburse for medical day programs, and grant funding has begun to support less intense and structured social day care demonstration programs, in order to examine the benefits of this model. While social day care often does not have a medical/nursing component, these programs include case management, substance use and mental health services, and meals. In addition, social day care provides the benefit of a structured milieu, though less so than ADHC.

CONCLUSION

We raise the following questions from a state policy perspective. What is in the future of long-term care needs of New York State residents with HIV infection?

How can these needs be met in the least restrictive environment possible? How can these needs be met in a financially responsible manner?

The Department of Health made funds and technical support available to create an infrastructure for chronic care services. If HIV disease remains responsive to antiretroviral therapy, and mortality and morbidity rates for people with HIV/AIDS remain low, how can the chronic care needs of people with HIV/AIDS be met best? The challenge will be to determine the appropriate mix of chronic care services that will be needed. Assessing long-term care needs and crafting programs that truly meet these needs is a formidable task. Blustein et al note that:

The health service delivery system has not yet developed criteria for determining who will fare best in each type of long term care setting and . . . how many people can be expected to need each of these different types of long term care.^{6(p32)}

In addition, development and change in the long-term care infrastructure for individuals with HIV illness require advance planning, and it remains unpredictable if the improvements in the clinical status of people with HIV infection will continue, or if morbidity and intense care needs will increase.

Chronic care services, in general, have been exempted from inclusion for capitated services under mainstream managed care and the managed care programs for HIV infected individuals for Medicaid recipients that are planned in New York State (Special Needs Plans). It remains to be seen if referrals, including patient acuity levels, to RHCs and ADHC will change when the HIV managed-care plans become operational.

Long-term care needs likely will change over this next decade. New York State health care planners will need to have great foresight and flexibility to meet the need for these services. While a large system of care will continue to be necessary, the exact shape and relative importance of the components of long-term care services for HIV-infected people 10 years from now is difficult to predict. Much will depend on the continued success of current treatment advances, as well as on the availability of community resources. State government needs to play an active role in ensuring that the long-term care needs of New York State residents with HIV/AIDS are met.

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