



U.S. Department of Health and Human Services  
Assistant Secretary for Planning and Evaluation  
Office of Disability, Aging and Long-Term Care Policy

# **SERVING A CHANGING POPULATION:**

## **HOME- AND COMMUNITY-BASED SERVICES FOR PEOPLE WITH AIDS**

September 1998

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This report was prepared under contract #PHS-282-92-0044 between DALTCP and Mathematica Policy Research, Inc. For additional information about this subject, you can visit the DALTCP home page at [http://aspe.hhs.gov/\\_/office\\_specific/daltcp.cfm](http://aspe.hhs.gov/_/office_specific/daltcp.cfm) or contact the office at HHS/ASPE/DALTCP, Room 424E, H.H. Humphrey Building, 200 Independence Avenue, S.W., Washington, D.C. 20201. The e-mail address is: [webmaster.DALTCP@hhs.gov](mailto:webmaster.DALTCP@hhs.gov). The Project Officer was Gavin Kennedy.

# **SERVING A CHANGING POPULATION: Home- and Community-Based Services for People With AIDS**

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In the early 1980s, when AIDS first appeared, it was an unfailingly acute and fatal disease. Since then, advances in AIDS-specific medical expertise and treatment have increased life expectancy for people with HIV and AIDS (although the disease remains fatal). As a result, AIDS treatment has shifted from an acute- to a chronic-care model.

These changes have broadened the need for different types of home- and community-based services to help people lead longer and fuller lives with AIDS. Services such as assistance with daily living activities and the provision of home-delivered meals have long been an integral part of AIDS care. Because of improved health and functioning, however, people with AIDS now need help with activities such as adhering to complex treatment regimens, returning to work, and caring for families.

This publication summarizes the results of a study, conducted by Mathematica Policy Research, Inc., for the U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, to examine the availability of and funding for home- and community-based services for people with AIDS. The study, which also helped develop a research agenda, had three components: (1) a literature review; (2) case studies; and (3) an analysis of use and reimbursement patterns for New Jersey Medicaid beneficiaries with AIDS.<sup>1</sup>

## **POLICY IMPLICATIONS IN BRIEF**

In identifying the challenges health care providers, planners, and policymakers face in dealing with the changing epidemic, researchers at Mathematica® noted a need for:

- Better information about service use and costs to deal with an environment increasingly dominated by cost control
- Concrete strategies for implementing managed care for people with AIDS
- A cohesive policy that addresses the health care needs of people with all types of chronic illnesses

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<sup>1</sup> The Medicaid data analysis was conducted by the AIDS Research Group of the Institute for Health, Health Care Policy, and Aging Research at Rutgers University.

U.S. AIDS Cases, 1981 to June 1996			
AIDS Cases During the Period	1981 to 1987	1988 to 1992	1993 to June 1996
Number	50,352	203,217	294,533
Percentage by Sex			
Male	92	88	82
Female	8	13	18
Percentage by Transmission Risk Group			
Men who have sex with men	64	55	45
Injection drug users	17	24	27
Men who have sex with men and inject drugs	8	7	6
Heterosexual	3	6	11
Others	8	8	12
Percentage by Race/Ethnicity <sup>a</sup>			
Non-Hispanic white	60	51	42
Non-Hispanic black	25	31	38
Hispanic	14	17	19
<b>SOURCE:</b> Centers for Disease Control and Prevention.			
a. Percentages do not sum to 100 because "other" racial groups are not included.			

## EVOLUTION AND FINANCING OF THE EPIDEMIC

In the early days of the epidemic, the typical person with AIDS was a white man who had contracted HIV through sexual contact with another man. However, the epidemic has increasingly and disproportionately affected women and people from racial or ethnic minority groups. More and more, the mode of transmission for the disease has been injection drug use. Meanwhile, improved medical care and pharmaceutical treatment have extended the lives and improved the health of many people with AIDS, leading, in 1996, to the first decline in deaths since the start of the epidemic.

Changes in AIDS treatment and in the characteristics of the AIDS population have had profound and interrelated effects on the use of home- and community-based services by people with AIDS. Longer life expectancies mean that people use needed services for a longer time. Enhanced treatment has also improved health and decreased levels of functional impairment for many people, which in turn has led to a decrease in their use of such traditional home- and community-based services as home-delivered meals and personal care. At the same time, better treatment has boosted the need for other types of support, such as assistance with adhering to complex treatment plans and returning to work. Meanwhile, the increased incidence of AIDS among people with low incomes, people with substance abuse problems, and women and families has amplified the need for greater interactions between home- and community-based service providers and substance abuse treatment, mental health, family services, and public assistance systems.

Medicaid, Medicare, and the Ryan White Comprehensive AIDS Resources Emergency Act have been the major public funding sources for HIV/AIDS care during the 1990s. Although 1995 Medicaid spending for AIDS care was only about two percent of total Medicaid spending, the spread of AIDS among low-income people has placed a growing burden on both the Medicaid and Ryan White programs, most recently to fund costly protease combination therapy. As the epidemic changes, these programs must also reconsider their eligibility and service coverage criteria, to reduce disincentives to work and increase flexibility in meeting chronic care needs, which typically vary in intensity and type over time.

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Public programs have sought ways to increase access to home care for beneficiaries with chronic conditions that put them at risk of institutionalization. For example, Medicaid programs have used Home- and Community-Based Service waivers allowed under Section 1915(c) of the Social Security Act. Part of this study compared home care use and costs for participants in New Jersey's AIDS waiver program with those for Medicaid beneficiaries with AIDS who received home care under regular Medicaid between 1988 and 1996. The analysis suggested that the waiver program's approach, which focused on case management, may have reduced existing disparities in home care use between beneficiaries from different racial/ethnic and transmission groups. For example, for beneficiaries receiving regular Medicaid services, there were statistically significant differences between blacks and whites and between injection drug users and nonusers. These differences did not exist for participants in the waiver program. The findings suggest that case-managed home care may be an important tool for increasing access to care in an increasingly diverse AIDS population.

The recent trend among Medicaid programs to rein in escalating costs by enrolling beneficiaries in managed care plans has had, to date, only a modest effect on people with AIDS. Many states exclude individuals with disabilities or chronic illnesses--like AIDS--from managed care. In addition, although Medicaid covers many of the home- and community-based services that people with AIDS need, most Medicaid managed care plans exclude these services from capitation arrangements. As a result, little is known about how best to provide the full range of AIDS-related services in a managed care environment. The spread of Medicaid managed care also raises questions about whether and how to integrate services currently provided with Ryan White funds for Medicaid beneficiaries who enter managed care.

## **PLANNING AND POLICY IMPLICATIONS**

The challenges facing providers, planners, and policymakers today in the wake of a changing AIDS population and evolving service environment present implications in three major areas, discussed next.

## INFORMATION NEEDS

In an environment that focuses increasingly on cost control, program planners and policymakers need the following information to make decisions about home- and community-based services for people with AIDS:

- Basic descriptions of service use, costs, and variations over time, by geographic region and by funding source
- Further breakdowns of service use by particular groups of people with AIDS, such as those defined by gender, minority status, income, the stage of the disease, HIV risk group, use of particular pharmaceutical treatments, presence of behavioral comorbidities, and whether an individual is homeless or has a family that would be affected by the disease

Although basic information about service use patterns is sorely needed, more sophisticated analyses--offering evidence that a particular program, approach, or financing mechanism provides cost-effective care--would also help guide the decision-making process in the future.

The need to develop practice guidelines for home- and community-based services also bears further consideration. Practice guidelines, such as those now widely used in home health care, could clarify the goals and tasks of home- and community-based services. Guidelines could be one part of a strategy to coordinate services more effectively across systems.

## INTEGRATED APPROACH UNDER MANAGED CARE

While managed care holds the potential to better coordinate care for people with AIDS, there are many challenges to its implementation, including:

- Formulating risk management strategies that offer plans incentives to enroll people at risk of high costs
- Developing mechanisms to ensure high-quality AIDS treatment

*. . . basic information about service use patterns is sorely needed [as is] evidence that a particular program, approach, or financing mechanism provides cost-effective care . . .*

However, planners face additional challenges in addressing the needs of people with AIDS for home- and community-based services. If managed care planners decide

to include these services under capitation, fundamental questions exist about how to implement and integrate them. For example, who should coordinate and oversee their use--medical or social services providers? Small, neighborhood-based or larger, more comprehensive providers? Even less is known about whether and how to integrate Ryan White funding and services under managed care. To clarify some of these issues, demonstrations of managed care for people with AIDS should integrate home- and community-based services with medical care.

## **NEEDS OF PEOPLE WITH CHRONIC ILLNESSES**

The issues that surround delivering AIDS-specific home- and community-based services illustrate a larger need to develop and implement a cohesive policy that addresses the needs of people suffering from all types of chronic illnesses. Health care and support service systems for people with chronic illnesses need to be flexible enough to:

- Permit the intensity of service delivery to vary as the needs of individuals change over time
- Minimize incentives to provide care at inappropriate levels

Medicaid and Medicare currently include incentives that run counter to these goals. Programs such as these must give people with chronic illnesses the flexibility to return to work when they are well enough, without jeopardizing access to the very services that make them healthy enough to work. This is a particular dilemma for people with AIDS who are taking protease inhibitors funded by Medicaid or Ryan White.

Support services for poor people with chronic illnesses, including AIDS, must mesh more closely with public assistance, housing, and family services. People's subsistence needs must be met before health and traditional support services can be put in place. Similarly, support services for people with chronic illnesses and behavioral problems must work more closely with mental health and substance abuse treatment providers.

The similarities between the needs of disadvantaged people with AIDS and those of disadvantaged people with other types of chronic illnesses raise questions about the equitability of support services funding. The Ryan White program has demonstrated that important service and funding gaps had to be filled in order to help poor people with AIDS. These gaps almost surely exist for all poor people with severe chronic illnesses.

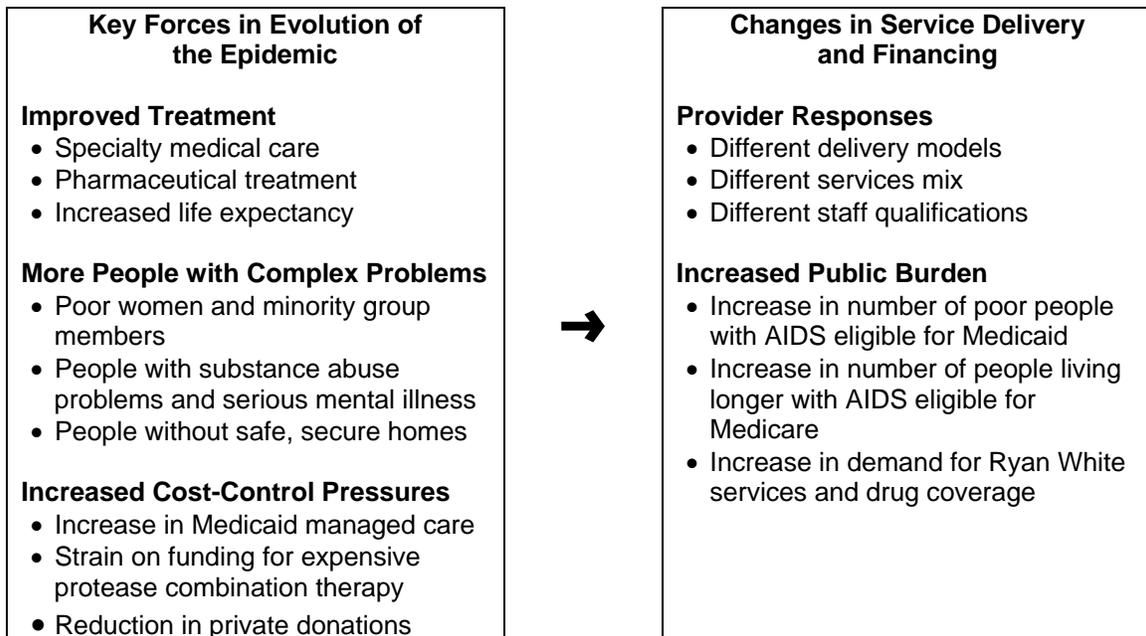
## **RESEARCH AGENDA RECOMMENDATIONS**

The planning and policy implications discussed here give rise to the following recommendations for future research.

**Building Databases.** There is a clear need both for large representative databases that can provide timely descriptions of home- and community-based service use by different groups of people with AIDS, and for focused data collection to identify and evaluate promising interventions. Large administrative databases are representative and comprehensive, but they usually lack detailed data describing individual characteristics. Using them can also involve waiting for processing lags, which keep these databases from being as timely as desirable. Provider databases, on the other hand, have the potential to add characteristics data and to be more timely, but they describe highly specific populations and may not include complete characteristics data. Research should examine the feasibility of developing *combined* administrative databases, supplemented by provider data.

*[Important service and funding gaps] almost surely exist for all poor people with severe chronic illnesses.*

**Identifying Specific Intervention for Evaluation.** This study identified a number of interventions that could be considered for formal evaluation, such as short-term, transitional residential treatment adherence assistance, and integrated mental health and AIDS services. A request for proposals, disseminated widely to AIDS providers, could be used to identify additional interventions. To encourage as many responses and burden providers as little as possible, the RFP could ask providers to submit a two-page summary describing their ideas. A panel would then review each summary, and selected providers would be asked to submit a detailed proposal for consideration.



**Developing Managed Care Demonstrations That Include Home- and Community-Based Services.** AIDS-specific demonstrations are needed that include capitated home- and community-based services covered under regular Medicaid

benefits, Medicaid waivers, and Ryan White funding, to determine whether and how such arrangements can best be implemented. These demonstrations should also collect encounter data to describe patterns of service use under capitation. But first a number of hard questions, related to setting payment rates and identifying appropriate host organizations and a full range of service providers, must be answered.

**Developing Practices Guidelines and Quality Indicators.** Although the use of practice guidelines is growing in home health care, practice guidelines and quality indicators have not been used widely for other home- and community-based services. Research should investigate the feasibility of developing these tools. A first step might be to review the literature to identify guidelines and indicators that already exist. Next, meetings of experts and consumers could be convened, to discuss the desirability of developing or refining guidelines and indicators for specific services.

**Forging Better Links Between AIDS Services and Other Systems.** The level of contact between AIDS service providers and providers and entities in other systems--including substance abuse treatment, mental health, family services, and public assistance--has expanded in recent years, primarily through increased referrals between systems. Yet AIDS providers interviewed as part of our case studies noted a lack of information sharing, particularly between AIDS providers and those in the substance abuse treatment and mental health systems. Coordinating the work of these two systems in particular could pave the way for developing strategies to help people with substance abuse problems or mental illness adhere to AIDS treatment regimens. Research should investigate viable approaches for sharing knowledge and pooling resources between AIDS service providers and those in other systems with a large AIDS client base.

*... changes in service delivery that result from changes in welfare or immigration policy will wield a more direct effect on an AIDS population that is growing poorer.*

**Assessing Return-to-Work Regulations.** Although the Supplemental Security Income program provides public benefits for people working with a "severe impairment," it is not clear whether, or how, these benefits apply to people with AIDS who are being treated successfully with costly protease or other pharmaceutical therapy. Because AIDS medications are so expensive and the disincentive to work particularly strong, this area should be clarified. Existing regulations may need to be revised.

## LOOKING AHEAD

As AIDS increasingly becomes a disease of disadvantaged people, medical treatment and health-related support services are blending with traditional public assistance programs, such as food stamps and housing assistance. In the future, changes in service delivery that results from changes in welfare or immigration policy will wield a more direct effect on an AIDS population that is growing poorer.

As AIDS increasingly becomes a chronic rather than an acute disease, its management has come to resemble more closely that of other serious chronic conditions. Key challenges in developing cost-effective models of chronic-disease management include determining new ways to help individuals take responsibility for their own health, for example, by adhering to prescribed treatment. Policymakers must also assess how to provide the assistance and financial support people need to assume this responsibility.

Other types of services may have to play a bigger role in the delivery of home- and community-based services for the AIDS population in the future. These services include substance abuse treatment, mental health services, assisted or supportive living, interventions with families, assistance with returning to and maintaining work, and help locating safe and secure housing.

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