Medicaid home and community-based waivers for acquired immunodeficiency syndrome patients

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Acquired immunodeficiency syndrome (AIDS), an increasingly significant health problem, presents a special challenge to Medicaid programs. Analyzed in this article is one particular approach to providing services for Medicaid-eligible AIDS patients: the Medicaid home and community-based (section 2176) waiver program, authorized by the 1981 Omnibus Budget Reconciliation Act and amended in 1985 to include persons with AIDS. The authors conclude that the AIDS-specific waiver is an attractive program for the States, but that changes in program administration and in how cost effectiveness is determined would likely facilitate broader acceptance by the States.

Introduction

Organizing and financing health care services for persons with acquired immunodeficiency syndrome (AIDS) have become important health policy concerns. As costs continue to escalate, decisionmakers are searching for more cost-effective ways, including alternatives to hospital inpatient care, to treat AIDS patients.

The burden of providing services to persons with AIDS falls increasingly on the Medicaid program. A person with a diagnosis of AIDS is deemed presumptively disabled and, if income and asset criteria are met, is thus eligible for Supplemental Security Income (SSI) benefits. The most important SSI benefit may be categorical eligibility for health care through a State's Medicaid program.[1] The incapacitating nature of the disease and the associated high medical and therapeutic costs can quickly exhaust personal resources. AIDS patients who do not initially qualify for Medicaid through SSI because their income and assets are too high may meet the criteria for eligibility as medically needy or may spend down to qualify. Further, the broadening of Aid to Families with Dependent Children (AFDC) eligibility for women and children in recent Omnibus Budget Reconciliation Acts (OBRAs), some of whom may have or will develop AIDS, further enlarges the pool of Medicaid eligibles. In addition, the development of pharmaceuticals that extend the lives of AIDS patients is likely to strain further the Medicaid budget for the costs of both providing the drugs and the additional medical care needed for longer survival times.

As a payer of last resort, Medicaid agencies covered an estimated 40 percent of all AIDS patients and as much as 25 percent of all AIDS bills in 1987 (Roper, 1987). Pascal (1987) estimates that the costs of providing care to AIDS patients will absorb up to 5 percent of a State's Medicaid budget during the 1990s; and Pascal, Cvitanic, and Bennett (1989) indicate that many high caseload States may see additional AIDS-related increases of 10-15 percent in Medicaid expenditures during this period.

The challenge to State Medicaid agencies of providing adequate health care services to the growing AIDS population is complicated by two opposing tensions in allocating resources. First, agencies face resource cutbacks and limitations at both the Federal and State levels. Second, Medicaid agencies have been simultaneously directed by the various OBRAs to expand eligibility (and thus expenditures) for services, especially for mothers and children. Thus, Medicaid agencies are competing with other State programs for general revenue funds to maintain basic programs as well as seeking additional funds to support federally mandated expansions of eligibility.

Medicaid agencies have several alternatives under which they may organize health care services for AIDS patients. These alternatives include the following:

- Inpatient, outpatient, and other Medicaid services on a traditional basis.
- A wide range of additional optional services that would meet many of the patient's needs.
- Home and community-based services for the disabled and other designated populations under a section 2176 waiver.
- Special services to an individual or a small group of like individuals under a model 2176 wavier.
- Noninstitutional services to the AIDS patient under an AIDS-specific 2176 waiver.

One promising alternative to traditional Medicaid services is through the Medicaid home and community-based waiver program. In Section 2176 of OBRA 1981, the Health Care Financing Administration (HCFA), the U.S. Department of Health and Human Services entity responsible for administering the Federal-State Medicaid program, was given the authority to waive certain Medicaid statutory and regulatory provisions for applicant States if alternative services could be offered on a budget-neutral basis, that is, without costing more than institutional services would cost and without impairing access to high-quality services.[2] The home and

[1]Income and asset criteria vary by State.

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[2]All States participating in the Medicaid program must meet certain Federal requirements, including the provision of comparable services on a statewide basis to all Medicaid eligibles, permitting a choice of provider, where possible. Waivers may exempt States from providing comparable services on a statewide basis, allowing States to target services to special populations.

community-based waiver program is intended to provide more appropriate services by diverting patients from institutional care to services provided at home or in the community. In 1985, the home and community-based waiver program was specifically amended to cover persons with AIDS.

The waiver program allows considerable State flexibility in defining the populations to be served and the range of services to be provided. Although HCFA has encouraged States to apply for AIDS-specific 2176 waivers, they have been slow in doing so. As of April 1, 1990, nine States have operational AIDS-waivers, and four have pending applications.

In this article, we review the results of a case study focused on the objectives of the waiver program, how it has been implemented by those States with operational AIDS waivers, and the reasons why most States have been reluctant to apply. The difficulties in measuring costs and cost savings for treating AIDS patients are addressed in this study.

Study design and methodology

The specific purposes of the study were to determine the status of the AIDS waiver among States; to identify reasons why some States applied for an AIDS-specific wavier and why others, with a substantial number of persons with AIDS, have not; and to assess State experiences in applying for and implementing the AIDS waiver. The project design consisted of studying all States with approved AIDS waivers, identifying and selecting representative nonwaiver States, and studying both AIDS-waiver and non-AIDS-waiver State responses to the use of home and community-based AIDS waivers during the period September 1988 through May 1989. Medicaid agency staff responsible for administering the AIDS waiver were interviewed by telephone or in person. For those States without AIDS-specific waivers, Medicaid agency staff responsible for administering other home and community-based waivers were interviewed by telephone.

We contacted the six States with AIDS waiver programs as of January 1, 1989: New Jersey, New Mexico, Ohio, Hawaii, South Carolina, and California. We also contacted a sample of 12 additional States and the District of Columbia to query their understanding of the waiver program and their intentions regarding a waiver application. The States contacted were Connecticut, Florida, Georgia, Illinois, Maryland, Massachusetts, Michigan, New York, Pennsylvania, South Dakota, Utah, and Texas.[3] The sample included two States with significant AIDS populations (New York and Florida), one with a Medicaid match rate higher than the usual 50 percent (Georgia), and two with a more limited number of optional Medicaid services (Texas and Pennsylvania), all potential motivations for seeking a waiver. Utah and South Dakota, each with a low number of reported AIDS cases, were chosen to provide comparative information on States not likely to be candidates for the AIDS waiver.

[3]Florida (as of July 2, 1989) and Pennsylvania (as of April 1, 1990) now have an approved waiver. Illinois has a waiver application pending HCFA approval, and Texas withdrew its waiver application.

Purpose and description

The rising costs of the Medicaid program, a significant portion of which is attributed to the increasing costs of institutional care, prompted Congress to include section 2176, the home and community-based waiver option, in OBRA 1981.[4] Waivers permit States to target specific Medicaid services to particular classes of patients—for example, the aged, disabled, mentally retarded, mentally ill, and persons with AIDSs—and to limit services to particular geographic areas. By favoring the provision of services in the home or community, waivers are intended to avoid the higher costs of institutionalization.[5]

Nine basic service categories can be provided as home and community-based services: case management, homemaker, home health aide, personal care, adult day care, habilitation, respite care, day treatment or other partial hospitalization services, and psychosocial rehabilitation and clinic services (whether or not furnished in a facility for individuals with chronic mental illness). A 10th category, "other," offers Medicaid agencies considerable flexibility in designing a broad range of services especially suited to the AIDS population.

We turn now to a review of the States with operational waivers and their motivations for applying for an AIDS waiver. We look at the characteristics of their AIDS populations, the scope and coverage of their Medicaid programs, services provided under their AIDS waivers, their experiences in administering and monitoring the waivers, benefits they attribute to the waiver, and their concerns about the waiver. We then consider States without AIDS waivers, focusing on their reasons for planning to apply or not to apply for a waiver.

States with operational waivers

Motivations for applying for waiver

States reported that one or more of the following factors motivated them to apply for an AIDS waiver:

- The projected number of AIDS cases likely to occur in their States in the near future.

[4]This amendment appears as Section 1915(c) of the Social Security Act.

[5]An additional type of 2176 waiver, the model waiver, was instituted in 1982. Prior to 1982, a patient such as a ventilator-dependent child whose parents may have preferred to provide home care but whose deinsitutionalization would have resulted in the loss of SSI and Medicaid eligibility sought an individual waiver from the Department of Health and Human Services (DHHS) for the requirement of institutionalization as a condition for Medicaid eligibility. These case-by-case waivers are referred to by some as "Katie Beckett" waivers, named for a child faced with this situation. DHHS introduced the model waiver concept to allow States to "batch" these individual requests, including as many as 200 individuals with the same condition under a model waiver. At least two States, Illinois and North Carolina, are currently using the model waiver to provide services to individuals with AIDS.

- The potential for avoiding the considerable costs of institutionalization in favor of services that could, presumably, be offered to the AIDS population less expensively and more appropriately in the home or community setting, inasmuch as AIDS patients do not require continuous hospital or nursing home care.
- For those States with a high Medicaid Federal match rate, the ability to obtain more funds for a specific population, those with AIDS.
- The ability to target services to a unique population.
- A commitment to explore any option that would broaden the array of health services provided to the Medicaid population.

Perhaps the most important factor in a State's decision to seek a waiver was the projection of its future AIDS populations, based on incidence and prevalence data available in 1986 and 1987. Hawaii, New Mexico, and Ohio indicated that these early projections of AIDS patients likely to need Medicaid services over the next several years were cause for concern. They recognized that they could meet such potential needs only with concerted advanced planning involving as many service providers as possible.

New Jersey received the first approved waiver, with a starting date of March 1, 1987. New Mexico received the second, on July 1, 1987, followed by Ohio (January 1, 1988), Hawaii (March 1, 1988), South Carolina (August 1, 1988), and California (January 1, 1989).[6]

Table 1

Reported cases of acquired immunodeficiency syndrome (AIDS) in waiver States since June 1981, rank order among States reporting cases, and rates per 100,000 population, by State

State	Total cases reported as of July 31, 1989	Rank among States	Rates per 100,000 population
California	20,478	2nd	20.7
New Jersey	7,074	4th	30.8
Ohio	1,405	12th	4.4
South Carolina	561	26th	7.3
Hawaii	389	29th	12.2
New Mexico	197	38th	5.4

SOURCE: Centers for Disease Control: HIV/AIDS Surveillance Report, Aug. 1989.

Characteristics of the population

The number of AIDS cases diagnosed since June 1981 in the waiver States is shown in Table 1. States with services provided under an AIDS waiver include those in both the top and bottom quartile of total numbers of reported AIDS cases.

The subpopulations affected by AIDS differ from State to State (Table 2). The homosexual and bisexual populations and the intravenous drug user (IVDU) population are unevenly distributed among the States. The incidence of AIDS generally differs by age categories and by racial and ethnic groups. However, the incidence of AIDS among racial and ethnic groups may be disproportionate to the numbers of those groups within the larger population.

In California, Hawaii, New Mexico, and Ohio, the largest affected subpopulations to date are the homosexual and bisexual male populations (Table 2). South Carolina estimates that one-half of its AIDS population is either homosexual or bisexual. By contrast, the IVDU is New Jersey's largest subpopulation, accounting for 56 percent of the reported cases. New Jersey ranks second in the number of children diagnosed with AIDS, behind first-ranked New York, which does not have an AIDS waiver.

Coverage provided by Medicaid programs

The Medicaid program, as a joint Federal-State endeavor, requires all participating States to cover such services as inpatient hospital, outpatient hospital,

[6]After our study was completed, five additional States were approved: Missouri (June 13, 1989, to become operational July 1, 1989), Florida (approved July 21, 1989, to become operational November 1, 1989), Pennsylvania (to become operational April 1, 1990), Washington, and Iowa. Two States have applications pending HCFA approval: Colorado and Illinois.

Table 2

Percent distribution of acquired immunodeficiency syndrome, by subpopulations, race, and State: October-December 1988

Subpopulation and race	California	Hawaii	New Jersey	New Mexico	Ohio	South Carolina
			Percent distribution			
Homosexual or bisexual	80	82	28	97	73	50
Intravenous drug user	4	3	56	NA	7	19
Homosexual and intravenous drug user	9	2	NA	NA	7	~7
Hemophiliac	1	<1	3	NA	4	NA
Transfusion	2	2	NA	NA	3	NA
Heterosexual	2	2	8	NA	3	NA
Pediatric	<1	<1	3	NA	NA	NA
Black	12	2	45	4	0	54
Hispanic	13	4	15	27	22	0
White	74	72	38	64	78	46
Other	1	20	2	5	0	0

NOTE: NA is not available.

SOURCE: Telephone interviews with Medicaid 2176 waiver staff.

Table 3

Number of acquired immunodeficiency syndrome (AIDS) patients in December 1988, rank order of cases, Federal match rate and available optional Medicaid services, by waiver States and selected nonwaiver areas

States	Number of patients December 1988	Rank of reported cases December 1988	Federal match rate 1985	Number of optional Medicaid services	Medically needy program
Waiver					
California	5,919	2d	50.0	29	Yes
Hawaii	105	29th	50.0	22	Yes
New Jersey	2,533	5th	50.0	28	Yes
New Mexico	59	38th	69.4	16	No
Ohio	529	12th	55.4	25	No
South Carolina	172	26th	73.5	17	No
Nonwaiver					
Connecticut	427	15	50.0	24	Yes
District of Columbia	512	10	50.0	25	Yes
Florida	2,714	3	58.4	17	Yes
Georgia	800	8	67.4	13	No
Illinois	1,032	6	50.0	27	Yes
Massachusetts	711	9	50.1	30	Yes
Maryland	552	11	50.0	17	Yes
Michigan	457	17	50.7	26	Yes
New York	6,938	1	50.0	26	Yes
Pennsylvania	890	7	56.0	16	Yes
South Dakota	7	49	68.3	16	No
Texas	2,239	4	54.4	15	No
Utah	75	37	70.8	26	Yes

SOURCES: Centers for Disease Control: AIDS Weekly Surveillance Report, Dec. 1988; Health Care Financing Administration: *Medicare and Medicaid Data Book, 1986;* Congressional Research Service: Medicaid Source Book: Background Data and Analysis, Nov. 1988.

physician, laboratory, X-ray, and, for those 21 years of age and over, skilled nursing facility and home health care. States may expand the scope of their Medicaid programs—and thus increase access to additional services—by covering up to 30 types of optional services (e.g., intermediate care, prescribed drugs, and transportation). Table 3 contains the number of optional services covered by States in this study. The comprehensiveness of the Medicaid programs in each of the waiver States ranges from 29 optional services in California to 17 in South Carolina and 16 in New Mexico.

States may also increase access to Medicaid by broadening the definition of eligibility for services. Thirty-six States have established medically needy programs to cover medical services for persons who fit one of the categories for Medicaid eligibility (aged, blind, disabled, and families with dependent children) but whose incomes and assets are in excess of the standards for categorically needy coverage and below the medically needy standards established by the State. Among the AIDS waiver States, California, Hawaii, and New Jersey have Medicaid programs for the medically needy. (Florida and Pennsylvania, two of the three States with the most recently approved AIDS waivers, also have medically needy programs.)

Services provided under waivers

Table 4 contains the list of services provided to AIDS patients by the AIDS waiver States. Hawaii, with 13 services targeted to AIDS patients, offers the widest array of services; and Ohio, with 12 services, is second in scope. New Mexico, with five services, has the narrowest range of services among the six States. Five of the six States provide case management, personal care, and adult day care as part of their waiver services, and four of the States provide some additional services for foster children.

Experiences in administering waivers

Medicaid staffs in waiver States were asked to describe their experiences in administering the waiver program, focusing on operational issues and comparisons between initial projections of patient utilization and actual experience. Of the approved waivers, only four have been in operation long enough for States to comment on their experiences. Hawaii's waiver was approved for operation in March 1988 (later changed to April 1988), but the State has had difficulties in contracting with providers and did not become operational until April 1989. California's waiver became operational on January 1, 1989, so there is little experience to report to date.

We asked program administrators about their experiences with the range of approved waiver services and what services they would consider adding or terminating when they amend or renew their waivers. The answers varied by State. New Mexico staff, in preparing their application, were assured that transportation to medical services would be provided by an AIDS support group, but the support group has not followed through on its commitment; thus, New Mexico is considering adding transportation services in the future. Hawaii, though not operational at the time of this study, is considering changes in its proposed services for drug addicts. Their conversations with the New Jersey waiver staff have alerted them to the enormous expense of attempting to

Table 4

Services provided to patients with acquired immunodeficiency syndrome, by the waiver States

Services	California	Hawaii	New Jersey	New Mexico	Ohio	South Carolina
Total	7	13	6	5	12	7
Case management	X	X	X	X	X	
Homemaker	X			X	X	
Home health aide						
Personal care		X	X	X	X	X
Adult day care		X	X	X	X	X
Habilitation		X			X	
Respite care		X			X	
Services for chronically mentally ill						
Other:						
Adaptive or assistive equipment					X	
Attendant care	X					
Counseling or training		X				X
Nutritional					X	
Psychological	X				X	
Emergency alarm response system		X				
Home delivered meals		X			X	X
Hospice						X
Medical supplies					X	
Minor home adaptations	X					
Moving assistance		X				
Narcotic and drug abuse treatment		X	X			
Private duty nursing			X	X		X
Screening and assessment						
Skilled nursing facility	X	X				
Supervision or supplement foster care	X	X	X			X
Transportation		X			X	

SOURCE: Health Care Financing Administration: Home and Community-Based Service Waivers reports. Bureau of Eligibility, Reimbursement, and Coverage regular reports.

Table 5

Projected and actual utilization of 2176 waiver services provided to persons with acquired immunodeficiency syndrome, by State

State	Year 1		Year 2		Year 3
	Projected	Actual	Projected	Actual	Projected
	Number of persons served				
California	788	NA	963	NA	1,138
Hawaii	165	0	298	NA	528
New Jersey	350	237	600	697	1,000
New Mexico	75	48	75	NA	~200
Ohio	47	12	77	NA	~100
South Carolina	500	[1]250	NA	NA	NA

[1]Estimated.
NOTE: NA is not available.

SOURCE: Medicaid 2176 waiver staff for California, Hawaii, New Jersey, New Mexico, Ohio, and South Carolina.

provide physician-administered methadone treatments in the home. South Carolina has appointed a task force to study its scope of services as it gains more experience with the waiver.

New Jersey's Medicaid staff would like to expand eligibility beyond the current Medicaid requirement for a Centers for Disease Control (CDC) diagnosis of AIDS to also include all seropositives. They would also like to include hospice care (which is not covered by Medicaid in New Jersey) and would like to see more skilled nursing facilities and boarding homes for AIDS patients. As an alternative to additional nursing and boarding home beds, they are considering adding respite care (for 30-day coverage). New Jersey has identified a need to develop home services for adolescents, perhaps even arranging for special homes.

As one measure of experience with a waiver, we asked States to assess the accuracy of their projections of patient utilization against their actual experiences. In every instance, the projections for utilization for the first year considerably exceeded the actual utilization. Table 5 contains the projected utilization for the 3-year waiver period and, where applicable, the actual experience. New Jersey is the only State with 2 years' experience; their actual utilization in the second year did exceed their projection by 16 percent. Of those States for which data are available, New Mexico and New Jersey appear to have most closely met their utilization projections, providing services to about 64 and 67 percent, respectively, of the number of clients they projected they would serve.

The independent evaluations required of the AIDS waiver, when they are available, may provide further

insight into the States' experiences in administering and monitoring the waiver.

Benefits of waivers

States identified several benefits that they believe derive from the AIDS waiver. The waiver provides a focus for care for AIDS patients within the Medicaid program, allowing an agency to target appropriate services to this population without having to provide similar services to all Medicaid eligibles on a statewide basis. New Jersey, the most experienced AIDS-waiver State, credits their waiver program for the following benefits:

- Establishing a uniform system of services.
- Providing flexibility in service design and delivery.
- Establishing an AIDS treatment network.
- Identifying and rectifying gaps in service delivery.
- Providing home care to AIDS patients.
- Providing new services such as foster group homes for children.

Ohio points out that their waiver program, by focusing on in-home services, improves the quality of life of AIDS patients and is more sensitive to the patients' wishes than is institutional care.

Concerns about the waiver

The limited number of States with an operational waiver and the relative newness of this particular waiver limit the bases on which to analyze comprehensively the AIDS waiver progress. Nevertheless, some actual or potential problems were identified in discussions with these States that suggest why some States pursue the waiver option and others do not.

Waiver States consistently specified certain concerns related to the waiver program:

- The obligatory cost-effectiveness formula in waiver applications is complex, and data are not readily available in the requisite format.
- States with high IVDU and/or homeless populations expressed a special need for some form of bed and board care, although no waiver program covers this service.[7]
- The lack of standardized data collection methodologies across States makes program evaluation, program comparisons, and further research efforts increasingly difficult. (Nonwaiver States also indicated that these issues were of concern to them.)

Space does not permit a full discussion of the AIDS-waiver application and reporting processes (Jacobson, Lindsey, and Pascal, 1989). To apply, applicants must specify the scope of the waivers requested, describe the waiver participants, define the services, address safeguards and evaluations, describe the plan of care, provide freedom of choice assurances and documentation, and provide assurances and documentation for a waiver's cost-effectiveness. The cost-effectiveness formula, structured to compare total Medicaid costs with and without the waiver, has 14 separate cost components (Technical note). Many of the calculations pertain to care provided in a skilled nursing facility, an intermediate nursing facility, or an intermediate care facility for the mentally retarded and may seem of limited applicability to an AIDS patient. Annual reporting on expenditures, numbers of beneficiaries, and other program aspects is also required on HCFA Form 372, Annual Report on Home- and Community-Based Service Waivers.

Obtaining HCFA approval for an AIDS waiver does not necessarily guarantee rapid implementation and smooth operation. Hawaii's difficulty in becoming operational is noteworthy. The Medicaid agency initiated its application planning process with AIDS providers from the community and believed that consensus had been reached on the nature and scope of the waiver program. The Medicaid agency planned to contract out all services except case management. When it was time to develop contracts, however, the Medicaid agency found that facilities and institutions were reluctant to enter into contractual relationships. One factor, addressed more fully later, was financial: The amounts that the agency had allocated for personnel costs were not reflective of the current market. Another apparent factor was that provider organizations were fearful of being "branded" AIDS institutions, thus frightening away other types of patients. It appears that those individuals representing providers may not have had the authority to commit their agencies to contractual arrangements for care.

Despite these problems, States indicated that, based on their experiences to date, they would renew their waivers at the end of the first 3-year approval period. They are already considering adjustments and amendments to permit greater flexibility in their programs.

States without operational waivers

As was noted earlier, 12 States and the District of Columbia were contacted to determine whether they planned to apply for a waiver and, if not, why. Medicaid staffs in these areas expressed general approval of the AIDS waiver program as the best approach currently available for serving AIDS Medicaid patients. Despite the incentive of obtaining additional Federal dollars, expanding eligibility standards, and targeting services to only a subset of Medicaid eligibles, the majority of areas have not applied for an AIDS waiver.

Waiver application decisionmaking process

Reasons for not applying

The nonwaiver applicant States surveyed did not complain about the program content but raised several broad procedural objections. To begin with, almost every

[7]Despite State requests for assistance with housing and certain nonmedical services through the Medicaid program, such expansion would represent a major change in Medicaid as currently structured. Because States make the point that failing to provide such services actually increases Medicaid expenditures, it might be worth considering a small demonstration project for a discrete AIDS population, such as homeless IVDUs.

State complained about the application process itself. Even discounting traditional State desires to be free of Federal involvement in State programs, the breadth and intensity of the objections suggest more than simple carping. More than one State suggested, for instance, that the administrative burdens outweighed the benefits (and the influx of Federal funds), even where they valued the substantive program.

Many program administrators stated that the process is much too long and that adequate information could be obtained with less paperwork and justification for each detail. For example, Michigan rejected the AIDS waiver as a policy option because experience with other waivers suggested burdensome administrative requirements, particularly the cost reports, and insufficient latitude for the States. A common refrain on the administrative costs of the 2176 program was that, given the sometimes small waiver populations, the amount of staff time and resources allocated to administration and reporting is out of proportion with total spending for the home and community-based waiver.

A consistently expressed concern involved the need for greater flexibility in program administration (Pascal et al., 1989). Several States suggested that the reason more States do not apply is that the program does not allow sufficient State innovation. Not all States hold this view, though most would like to experiment with additional services such as board and care homes and different administrative structures.

The cost-effectiveness justification, including the cost reports, received repeated criticism, as did the length of time to complete the process. Even States that ultimately decided to apply raised these complaints. Indeed, many were frustrated because much of their time was spent on satisfying the cost-effectiveness formula instead of developing appropriate community-based services. Several representatives suggested that the budget neutrality intended by Congress has evolved into a need to show cost savings in implementation. As a result, some States maintain that too much emphasis is placed on cost savings and not enough on improving the mix and quality of services.[8]

Several States, including Massachusetts, New York, and Maryland,[9] did not apply because they were already providing similar services under State plans. Hence, they felt the AIDS waiver offered only marginal benefits over the services they were already providing to AIDS patients, and such benefits were offset by the added administrative costs and diminishing program flexibility. This is not to suggest that these States are without problems in serving AIDS patients. In New York, for example, there are problems with insufficient provider participation, particularly among nursing homes, reducing access for AIDS patients at the appropriate level of care.

As expected, the two sample States with a low AIDS incidence, South Dakota and Utah, have not seriously considered an AIDS waiver. It is unlikely that many low AIDS-incidence States will consider a waiver in the future, absent an increase in the AIDS population, because these States can provide necessary services to the current AIDS population through existing programs. In Utah, for example, AIDS patients are eligible for all Medicaid services including home health and nursing home services, with a physician acting as case manager.

Reasons for applying

Although the reasons for planning to submit an AIDS waiver application vary across States, one consistent motivation is programmatic. Each of the States planning to apply stated that it expected to provide a broader array of services more efficiently under the waiver.

In some States, the motivation is as much political (that is, they are under pressure from AIDS advocacy groups) as it is programmatic, because few States really expect significant cost savings. In other States, the primary motivations are programmatic. In Texas, for instance, the State is looking for greater efficiencies and a more appropriate array of services for unmet needs. Faced with restrictive nursing home admissions, restrictive home health requirements, and no case management, Texas Medicaid staff indicated that a waiver program could provide alternatives to hospitalization for AIDS patients.[10]

Likewise, Connecticut AIDS patients face an inadequate range of available services under current optional services, and an application is awaiting approval for State officials. Florida submitted an application, approved since this study was completed, because the State felt that the waiver program offered the best approach. As a result, the State expects to offer a wide range of services. Georgia also finds the array of waiver services substantively attractive. Its application is pending before the State legislature as a proposed amendment to the State Medicaid plan prior to submission to HCFA.

Discussion

Although each State decides whether to apply for an AIDS waiver based on factors that vary across States—including the incidence and prevalence of AIDS, prior experiences with a waiver, the extent of Medicaid optional services approved in the State's Medicaid plan,

[8]HCFA is responsible for assuring the budget neutrality of a waiver application and while projected cost savings, if they can be substantiated, are welcome, they are not required. Cost calculations are, however, carefully reviewed to ensure their defensibility, with unit costs, the number of days required for particular services, and the incorporated inflation factor(s) receiving particular scrutiny. This review process may have contributed to the perception that HCFA's emphasis is on cost savings rather than on budget neutrality. It is also possible that the process of obtaining legislative approval forces State agencies to project cost savings.

[9]Maryland appears to be a special case, however, because strict cost containment limits overall expenditures, hence limiting the ability to purchase additional services.

[10]In 1989, however, Texas withdrew its AIDS waiver application before HCFA had made a decision. Medicaid waiver staff indicated that they had difficulty in obtaining appropriate cost data to use in the formula. They have elected to initiate a small pilot study to generate need, cost, and utilization data and will reconsider applying for an AIDS waiver in the spring of 1991.

and the Federal Medicaid match rate—certain general observations are warranted by this study:

- Those States with proportionately larger AIDS populations seem to be more interested in the 2176 waiver program than those States with fewer AIDS patients.
- Those States with extensive Medicaid benefit programs seem less interested in applying for a waiver, even if they have a large AIDS population.
- Data availability varies across States, and the lack of available data confounds the waiver application process as well as the ability to determine the waiver's cost effectiveness.
- Projecting waiver utilization is difficult, given the evolving understanding of disease progression and conflicting attitudes about it.
- Achieving budget neutrality with the required cost formula is hampered not only by insufficient data but also by the increasing costs associated with obtaining health care providers in particular demand, such as nurses and personal caregivers.
- States with waivers intend to renew their waivers and plan to amend their service coverage.

When the expressed reasons for not applying are compared with the perceived benefits of currently operating AIDS waivers discussed earlier, an interesting anomaly emerges. One of the primary benefits mentioned by current waiver States is the program's flexibility. Yet one of the primary reasons States do not apply is a perceived lack of flexibility. This suggests that AIDS-waiver and non-AIDS-waiver States have different understandings of what services can be provided. Some nonwaiver States, for instance, suggested that nonmedical services were just as important as medical services for AIDS patients; yet these States felt that nonmedical services could not be provided under the waiver. From the list of services provided by the AIDS waiver States (Table 4), it is clear that at least some of these services (e.g., transportation), while facilitative in nature, are not strictly medical services.

The availability of data varies considerably among States. Some States have devised sophisticated data collection systems on the number of AIDS patients and services provided, and others have not even begun to collect adequate data. This presents a short-term problem in comparing programs across States and in measuring outcomes but gives HCFA an opportunity to assist in developing consistent data bases.

States find it difficult to project waiver utilization and program costs, not only because of the variation in data availability but also because of the difficulty in satisfying the complex cost-effectiveness formula. Hawaii projected that they would serve 165 patients in their first year, based on estimates of prevalence in the population. Although no AIDS patients had been served under the waiver program at the time of this study, the total number of AIDS patients diagnosed in Hawaii between June 1981 and December 1988 is 291, suggesting that their projections for the first year are high (Table 5). In Ohio, waiver staff suggest that at least two factors have influenced utilization. First, families and others appear to feel more responsibility and are more willing to care for AIDS patients than was earlier anticipated. According to the Ohio waiver staff, this change in behavior and attitude may be attributed in part to an increasing understanding and awareness of the disease, at least among those most directly affected by it. Second, azidothymidine therapy appears to have ameliorated, or at least delayed, the onset of AIDS symptoms. This means that fewer services may be required in the early stages of the disease, and AIDS patients may stay at work and keep their private health insurance longer.

Two cost-related issues held true across all States. First, attempting to demonstrate budget neutrality through the use of the required formula proved frustrating. States find the formula complex. They may have no precedent for deriving costs for services to be offered in the home or community as opposed to the costs for services offered in an institutional setting. New Mexico, for example, had only inpatient acute care costs as a standard, because long-term care facilities in that State refused, on the basis of licensure regulations at that time, to admit AIDS patients. Medicaid staff knew that the hospital-derived projected costs were high because AIDS patients do not need to be hospitalized for many phases of their illnesses, but no better data were available. South Carolina struggled with a way to cost out all the extra services that foster parents would provide to AIDS babies (but not to other foster care babies), without resolving this issue satisfactorily.

The limited research results available on the cost effectiveness of Medicaid's home and community-based waiver program, primarily the results of HCFA evaluation contracts, do not offer clear guidance on how Medicaid agencies can make the AIDS-specific waiver more cost effective (Jacobson, Lindsey, and Pascal, 1989).[11] With two important exceptions (programs in South Carolina and San Francisco), whether the literature reports on the waiver program, community-based care, or managed care in general, the conclusion is the same: The programs are not likely to result in substantial cost savings. No one suggests that community-based care is not an important component of a health care delivery system, just that it is not likely to generate significant cost savings.

An important question, therefore, is whether waiver programs for the AIDS population are more likely to resemble those in the few studies showing cost savings or those in the more numerous studies showing no savings. Are the purposes of the AIDS waiver different from the other waiver programs? Or, are there certain differences in the AIDS population that suggest that the waiver program may indeed be cost effective? Because hospital care is much more expensive per day than nursing home care, for example, $825 versus $115 (Pascal, 1987), the needed reduction in inpatient length of stay must be comparatively smaller for AIDS patients to justify the costs of the waiver program. At present, few nursing homes seem willing to admit AIDS patients. Thus, there may be little long-term care to be avoided with AIDS patients in any event. And because the probability of hospital use by AIDS patients is greater than the

[11]These studies were done prior to the amendment for the AIDS-specific waiver.

probability of nursing home use by the elderly (Benjamin, 1989), the opportunities for cost savings may be greater with AIDS patients.

The second cost issue relates to personnel costs for providing services. The nursing shortage and the commensurate increase in nursing salaries needed to secure staff have been problematic for providers who contract to provide services to Medicaid patients and who based their prices on the then-current market. This has been an acute problem, for example, in Hawaii. Both Hawaii and South Carolina have experienced difficulty in finding and retaining personal care aides; the low wage they are able to pay is a primary factor. Even though Hawaii trains personal care aides, few training slots have been filled. Medicaid staff suggested that the certification requirements for aides mandated by OBRA 1987 will only exacerbate this problem.

Based on our discussions with States, it seems clear that Medicaid agencies are searching for better ways to deliver services to AIDS patients. Some States find the AIDS waiver to be the appropriate vehicle for delivering services. Others are satisfied with current delivery systems, and still others are skeptical that the waiver affords the flexibility they seek.

Whether the program is being perceived as a cost-containment effort rather than a way to target services to a special population is the larger question. Programs must be developed with the specific needs of AIDS patients in mind, which often means meeting nonmedical needs. The problem is to match services needed by AIDS patients to those available under the 2176 program or, alternatively, to effect changes in the waiver program to increase its flexibility. In sum, States recommend that HCFA, within a framework of budget neutrality, should focus on program services and quality of care.

Conclusion

The responses from this State survey suggest that the AIDS-waiver program is a promising approach to meeting the health care needs of AIDS patients. Because the actual program experience is so limited, firm conclusions about the program are premature. Nevertheless, discussions with various State Medicaid representatives indicate considerable optimism that the AIDS-specific waiver can be an effective means of providing services to AIDS patients. Even States that declined to apply for a waiver were generally not critical of the underlying programmatic waiver approach. All States with operational waivers expressed their intentions to renew these waivers and, in some instances, to expand the scope of services provided.

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Technical note

Cost-effectiveness formula

The cost-effectiveness formula, structured to compare total Medicaid costs with and without the waiver, follows (U.S. Department of Health and Human Services, 1988):

$$\frac{(AxB) + (A'xB') + (CxD) + (C'xD') + (HxI)}{F+H} - \frac{(FxG) + (HxI) + (F'xG')}{F+H}$$

where

A = estimated number of beneficiaries who would receive the level of care provided in a skilled nursing facility (SNF), an intermediate care facility (ICF), or an intermediate care facility for the mentally retarded (ICF/MR) with the waiver.

B = Estimated annual Medicaid expenditure for SNF, ICF, or ICF/MR care per eligible Medicaid user with the waiver.

C = Estimated number of beneficiaries who would receive home and community-based services under the waiver.

D = Estimated annual Medicaid expenditure for home and community-based services per eligible Medicaid user.

F = Estimated number of beneficiaries who would likely receive the level of care provided in an SNF, ICF, or ICF/MR in the absence of the waiver.

G = Estimated annual Medicaid expenditure for SNF, ICF, or ICF/MR care per eligible Medicaid user in the absence of the waiver.

H = Estimated number of beneficiaries who would receive any of the noninstitutional, long-term care services otherwise provided under the State plan as an alternative to institutional care.

I = Estimated Medicaid payment per eligible Medicaid user of the noninstitutional services referred to in H.

A' = Estimated annual number of beneficiaries referred to in A who would receive any of the acute care services otherwise provided under the States plan.

B' = Estimated annual Medicaid expenditure per Medicaid eligible user of the acute care services referred to in A'.

C' = Estimated number of beneficiaries referred to in C who would receive any of the acute care services otherwise provided under the State plan.

D' = Estimated annual Medicaid expenditure per eligible Medicaid user of the acute care services referred to in C'.

F' = Estimated annual number of beneficiaries referred to in F who would receive any of the acute care services otherwise provided under the State plan.

G' = Estimated annual Medicaid expenditure per eligible Medicaid user of the acute care services referred to in F.

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