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Medicaid and End-of-Life Care

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Executive Summary—Medicaid and End-of-Life Care

Introduction

Medicaid provides health- and long-term care coverage to children, young adults, and older people with low incomes and few assets, or those impoverished by the high costs of health care. Especially through its funding for long-term care services—such as nursing home, home care, and hospice—Medicaid is a major source of financing for end-of-life care, the period of time when patients are terminally ill.

Research Methods

To supplement the limited research and data available on end-of-life care for Medicaid beneficiaries, we designed a qualitative study of Medicaid's role in caring for dying patients. We interviewed 23 national experts about Medicaid and end-of-life care, and focused our analysis on covered populations, benefits, reimbursement, and quality assurance. We also interviewed four experts from health-care systems that provide innovative palliative and hospice services to Medicaid beneficiaries. The innovative health-care systems were identified by asking experts for nominations of systems that make palliative services available to Medicaid beneficiaries who are likely to die within one year.

Findings

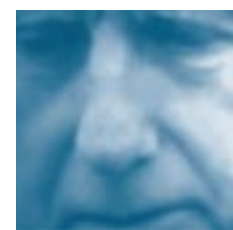
Eligibility—Medicaid uses Medicare's hospice requirement: a physician must certify that the patient has a life expectancy of six months or less if the terminal illness runs its normal course. The prognosis requirement creates barriers to access to care because

1) patients, their families, and physicians have difficulty discussing and accepting a prediction of death within six months, and 2) it can be difficult to make predictions of date of death with a great deal of accuracy, particularly for certain populations.

Benefits—As in Medicare, Medicaid beneficiaries who elect hospice must forgo “curative treatment” for their terminal illness and the line between treatment and palliation is not always clear-cut. Medicaid beneficiaries sometimes have difficulty accessing appropriate pain-relief measures because of prescription practices and Medicaid benefit limitations on the Medicaid drug benefit that some states impose. Even though they are not required by federal law to do so, some states are still requiring patients to give up home and community services when they opt for hospice care.

Quality Assurance—Medicare and Medicaid have quality standards governing hospices and nursing homes that can create problems for beneficiaries at the end-of-life. Hospices and nursing homes must have plans of care for nursing-home residents, which can be at odds with one another if the two providers do not coordinate their efforts. Quality assurance measures for nursing homes do not focus on pain management or palliative care, although the Health Care Financing Administration has begun to address these issues.

Payment—According to most non-governmental experts, the current Medicaid hospice rate for routine home care is too low to enable hospices to provide the most



Medicare and Medicaid have quality standards governing hospices and nursing homes that can create problems for beneficiaries at the end-of-life.

advanced types of pain relief, such as expensive chemotherapy and radiation treatments. Payment rates, although they have increased over time, are based on very old cost experience from the early 1980s that may no longer reflect current expenses.

The way in which Medicaid pays nursing homes for hospice patients causes a great deal of confusion. State Medicaid programs must pay at least 95 percent of the nursing-home rate for room and board directly to the hospice, which in turn pays the nursing home. Reportedly, nursing homes rarely accept less than 100 percent of the Medicaid room and board payment, causing a financial loss for the hospice. In addition, the nursing home's payment can be disrupted or payment to the hospice can be delayed when Medicaid switches from paying the nursing home for people who are already residents to paying the hospice.

Case Study Findings

Three of the four innovative health systems—the Community Medical Alliance, On Lok, and EverCare—are managed-care plans which receive capitated payments for serving a predominantly Medicaid population. These providers integrate health, long-term and end-of-life care using an interdisciplinary team approach to management of an enrollee's services. Thus, unlike the fee-for-service system or other managed care plans, enrollees in these health plans have an integrated system of care that does not require them and their families to navigate a complex health system on their own. The fourth provider nominated for its innovation was the Florida Hospice of the Suncoast. It is an example of a hospice that is taking the initiative to provide palliative services to Medicaid beneficiaries of all ages who do not want or are not ready for hospice.

Conclusions

A five-part strategy on the part of federal and state officials, providers, and foundations could help improve quality of care for dying Medicaid beneficiaries.

1. Develop better data about Medicaid beneficiaries and their experiences while dying. The data needed include information on causes of Medicaid beneficiaries' death, location of death, and utilization and cost of services during the last year of life, and how these compare to non-Medicaid decedents.
2. Encourage or require the health systems with which Medicaid contracts to pay more attention to end-of-life care. Managed-care organizations such as the Community Medical Alliance, On Lok, and EverCare have used the flexibility of capitation payments to provide needed services without reference to whether they fit specific fee-for-service categories. Dependence on managed care raises issues of freedom-of-choice of providers and capitation provides incentives for underservice, but this approach also gives providers the ability to use their funds in creative ways.
3. Explore ways to fund palliative care and make a range of pain-relief measures available through the fee-for-service system and try to improve delivery of end-of-life care in nursing homes. Experts persistently identified lack of explicit Medicaid coverage of palliative care to be a major funding problem. However, it is not clear how best to provide palliative care while addressing the need to restrain expenditure increases.
4. Improve pain management and end-of-life care in nursing homes and home care by examining Medicaid's current policies and modifying them to require participating providers to do such things as measure and

control pain. This is an attractive target of opportunity for improvement because of Medicaid's overwhelming role in financing long-term care services.

5. The current structure of the Medicaid-hospice benefit should be re-examined. The six-month prognosis requirement, reportedly inadequate payment rates, and the need for quality-assurance systems to address palliation and pain management in new ways were all identified as problem areas. Currently, no consensus exists about how best to address these issues.

The challenge for the future will be to harness Medicaid's purchasing power to improve the services that dying beneficiaries receive. Up to now, Medicaid has been the sleeping giant of end-of-life financing.

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Medicaid and End-of-Life Care

Introduction

Medicaid provides health and long-term care coverage to children, adults with disabilities, and older people with low incomes and few assets. Especially through its funding for long-term care services—such as nursing home, home care, and hospice—Medicaid is a major source of financing for end-of-life care, the period of time when patients are terminally ill. In addition to these services, Medicaid covers prescription drugs, physician, hospital, and nursing services, among others.

Although Medicaid plays a large role in financing a wide range of services, the program does not cover palliative care—a constellation of services including medical, psychological, social, and spiritual support for dying persons—as a separate benefit. Palliative care is available under the hospice benefit but only for beneficiaries who have a prognosis of death within six months and who agree to give up “curative treatment” for their terminal condition. Hospice beneficiaries receive such services as pain management, psychosocial services, and bereavement counseling from an interdisciplinary team.

This paper analyzes the role of Medicaid in end-of-life care, focusing on covered populations, benefits, reimbursement, and quality assurance. Because it has been the centerpiece of Medicaid policy on end-of-life care, much attention is devoted to the Medicaid hospice benefit. Four innovative delivery systems that provide palliative services

to dying Medicaid beneficiaries are also described to highlight possible ways to improve end-of-life care for people with low incomes.

Background

Medicaid is a means-tested entitlement program—jointly funded and administered by the federal and state governments—that provides a range of health and long-term care services. States have wide latitude in determining eligibility, benefits, and payment mechanisms for providers within broad federal guidelines. In fiscal year 1998, approximately 40.4 million people, including children, the aged, blind, and disabled, were enrolled in Medicaid (Urban Institute, 2000).

States must provide a core set of services that includes physician, hospital, nursing home, and home health services. States can limit the amount, duration, and scope of services, which may be problematic for dying beneficiaries. For example, Alabama covers only 16 hospital inpatient days and 14 doctor visits a year (Wiener et al., 1998). Texas limits the number of prescriptions that beneficiaries can fill to three a month, except for persons under age 21 or nursing home residents (National Pharmaceutical Council, 1998). In addition to the mandatory services, Medicaid programs can provide many optional services to beneficiaries, including hospice, outpatient prescription drugs, personal care, home and community-based services under waivers, and Programs of All Inclusive Care for the Elderly (PACE).¹



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¹ PACE programs provide comprehensive health-and long-term care services to frail nursing home-eligible enrollees under risk-based, capitated payment.



More than two-thirds of nursing home residents are dependent on Medicaid to finance their care

Medicaid's role in end-of-life care varies, depending upon the population under consideration. Most children and adults with disabilities who meet Medicaid's financial eligibility criteria rely almost exclusively on Medicaid for financing end-of-life care. However, elderly and younger disabled Medicare beneficiaries who are also eligible for Medicaid (i.e., dually eligible) rely on Medicare for coverage of physician, hospital, and most hospice services during the end-of-life. For the dually eligible population, many of whom reside in nursing homes, Medicaid supplements Medicare by paying Medicare's cost-sharing requirements and funding such services as outpatient prescription drugs and long-term care.

Most of the extant research on financing end-of-life care focuses on Medicare utilization and expenditures for the older population (Spillman and Lubitz, 2000; Gage et al., 2000). Very little data are available on utilization and expenditures during end-of-life for Medicaid beneficiaries, in part because of the difficulty in obtaining information from multiple payers for the younger population (Scitovsky, 1994). One study compared the use and costs of services at the end-of-life for aged Medicare beneficiaries and the dually eligible population in Monroe County, New York (Temkin-Greener et al., 1992). The 1988 data indicate that hospital and other Medicare expenditures for the aged dually eligible population were far higher than for persons who were only eligible for Medicare. Another study, which analyzed Medicare claims and eligibility data, estimated that 21 percent of Medicare beneficiaries who died from 1994 through 1998 were also eligible for Medicaid (Hogan et al, 2000). This same study analyzed 1992-1996 cost and use files from the Medicare Current Beneficiary Survey and estimated that, on average, during the last six months of life

Medicaid paid for 32 percent of dually eligible beneficiaries' health and long-term care costs.

Medicaid is a major source of financing for long-term care, especially nursing home care, at the end-of-life. Approximately 35 percent of older people who die use nursing home care during the last year of life and an unknown additional percentage use home and community-based services, such as personal care (Spillman and Lubitz, 2000). An analysis of the 1985 National Nursing Home Survey found that almost two-thirds of elderly nursing home admissions ultimately died either in a nursing home or hospital (Spence and Wiener, 1990).

More than two-thirds of nursing home residents are dependent on Medicaid to finance their care (American Health Care Association, 1999). For 2000, the U.S. Congressional Budget Office estimated that Medicaid funds 42 percent of nursing home care for the older population and 19 percent of this population's home care spending (U.S. Congressional Budget Office, 1999). In 1998, Medicaid spent \$44.4 billion on institutional long-term care and \$17.5 billion on home and community-based services, which represent 28 percent of total Medicaid expenditures for long-term care (Urban Institute, 2000).

Medicaid beneficiaries with disabilities have access to long-term care in the home, community, or institutions, although coverage of noninstitutional care varies a great deal from state to state. For example, Oregon devotes about half of its Medicaid long-term care spending to services in the home and community, while Indiana spends 90 percent of these funds on nursing home care (Urban Institute, 2000). In addition, each state sets its own unique financial and functional eligibility criteria for long-term care. Although

most states' functional criteria consider an applicant's difficulty with activities of daily living (ADLs), such as eating, bathing, and dressing, the definitions of ADLs and how they are weighted in determining eligibility varies markedly among the states. (O'Keeffe, 1996).

While the bulk of Medicaid funding for end-of-life care is for nursing home care, few nursing home residents receive hospice services. About 70 percent of nursing facilities have no residents using Medicare's hospice benefit and only four percent of facilities have at least five percent of their residents receiving hospice care (Petrisek, 1999).

Despite the large role of nursing homes in end-of-life care, the Medicaid benefit designed to serve dying beneficiaries is the optional hospice benefit, which closely tracks Medicare's benefit and provides a range of medical and palliative services to persons who have a prognosis of six months or less to live. According to the National Hospice and Palliative Care Organization (NHPCO), every state but Connecticut, Maine, Nebraska, New Hampshire, Oklahoma, and South Dakota covered hospice under Medicaid in 2000 (Connors, 2000). Maine subsequently decided to provide coverage starting in 2001 (Bangor Daily News, 2001).

When compared to the Medicare hospice benefit, Medicaid's hospice role is very small in terms of expenditures and number of persons served. Figure 1 shows that Medicaid accounted for only about seven percent of total hospice revenues and eight percent of hospice patients in 1995, while Medicare accounted for 74 percent of revenues and 65 percent of patients in the same year (National Hospice and Palliative Care Organization, 2001). In fiscal year 1998, about one percent of Medicare expenditures or \$2.2 billion went toward

hospice care for 360,000 patients, while Medicaid devoted much less than one percent of its federal and state spending or \$325 million to hospice services for 52,000 patients (Health Care Financing Administration, 1998; General Accounting Office, 2000; and Urban Institute, 2000).

Federal and state Medicaid spending on hospice, although small, has grown rapidly. Medicaid hospice expenditures amounted to \$129 million in fiscal year 1993 and rose to \$325 million by fiscal year 1998, almost tripling over that time period (*See Table 1 and Figure 2*). However, expenditures have plateaued in recent years and Medicaid hospice expenditures actually declined slightly between fiscal years 1997 and 1998. Medicare hospice expenditures also grew during this period. Medicare hospice payments almost doubled from fiscal year 1993 to fiscal year 1998, rising from \$1.15 billion to \$2.2 billion (National Association for Home Care, 1999; Health Care Financing Administration, 1998).

Medicaid federal and state spending for hospice care varies markedly among the states. For those states with a hospice benefit, total expenditures in fiscal year 1998 ranged from only \$572 in Tennessee to \$48 million in Florida and in Texas. Fiscal year 1998 spending for each beneficiary receiving hospice averaged \$6,284 for the U.S. and ranged from \$3,094 in Louisiana to \$18,022 in Michigan (*Table 2*). Hospice spending per person in the U.S. averaged \$1.20 and ranged from 9 cents in Oregon to \$3.25 in Florida.

In 1998, the total number of Medicaid hospice patients was 51,722, and ranged from only four in Arizona to 7,583 in Florida (*Table 2*). Demographic data on users of Medicaid hospice services are not available.

Research Methods

To supplement the limited research and data on end-of-life care for Medicaid beneficiaries, we designed a qualitative study of the Medicaid's role in caring for dying patients. We interviewed four sets of experts: eight national experts who were identified through their research on end-of-life issues; eight staff from the Health Care Financing Administration (HCFA); seven representatives of national organizations with a stake in end-of-life care, such as the National Association of State Medicaid Directors; and four experts from health care systems providing innovative palliative services to Medicaid beneficiaries.

Innovative health care systems in end-of-life care were identified by asking experts for nominations. No state was cited as having model Medicaid end-of-life policies. To be included in this study, delivery systems had to go beyond the provision of hospice care to make palliative services available to other Medicaid beneficiaries who are likely to die within one year. Each representative of the health system was asked to describe how the system identifies persons for receipt of end-of-life care, what the services are and how they are delivered, reimbursement rates, and quality assurance systems.

Policy Issues in Hospice Care for Medicaid Beneficiaries

In the Medicaid program, most of the policy focus on end-of-life care revolves around the hospice benefit, so the discussion with experts primarily dealt with this benefit. The limitations of the hospice benefit fall into several categories—eligibility, benefits, quality assurance, and payment.

Eligibility

For eligibility purposes, the Medicaid program uses Medicare's hospice requirement: a physician must certify that the patient has a life expectancy of six months or less if the terminal illness runs its normal course (State Medicaid Manual, Part 4, section 4305). As with Medicare, this medical eligibility requirement for hospice appears to be problematic, as evidenced by the small number of dying patients who receive the service and their length of stay in hospice—which is thought to be too short to provide the palliative services that dying patients need.

The prognosis requirement creates a psychological and practical barrier. Patients, their families, and physicians have difficulty discussing and accepting a prediction of death within six months, making them unlikely to use the benefit. This is particularly true for children, whose families and medical providers do not want to give up attempts at finding a cure and will try virtually anything to keep the child alive (Stephenson, 2000). Persons with AIDS generally are young, which increases their reluctance to accept a terminal prognosis (Cox, 1998).

Beyond the unwillingness to accept death, the practical problem is that it can be difficult for physicians to make predictions about death with a great deal of accuracy, particularly for certain populations. One expert estimated that the date of death is predictable within six months for only 20 percent of patients. Other experts noted that prognoses of children's death are particularly difficult. Children can go in and out of terminal illness phases and the curative process is likely to be very long, making it unclear whether they will ultimately recover from their illnesses (Stephenson, 2000). Likewise, the course of illness among

AIDS patients and the terminal phase of their illnesses can be quite difficult to predict (Cox, 1998), as it can be for patients with dementia.

To address some of the uncertainty related to prognosis, the NHCPO convened a group of experts to develop guidelines that providers could use to determine a patient's prognosis. HCFA made the guidelines available to Medicare fiscal intermediaries, who have tended to interpret them as rules (Lynn, 2001). However, the guidelines had not been distributed to state Medicaid programs as of December 2000.

Recent federal legislation—Section 322 of The Benefits Improvement and Protection Act (BIPA) of 2000—addresses the uncertainty surrounding prognosis by clarifying that the basis for the physician's certification is his or her own clinical judgment regarding the normal course of an individual's terminal illness. This is intended to alleviate concerns that a physician would be held liable if it was later determined that his or her clinical judgment may have been inaccurate. The same section in BIPA requires the Secretary of Health and Human Services to conduct a study regarding the appropriateness of the certification rule, taking into account this recent change in the law.

Although the non-governmental experts generally agreed that the six month prognosis requirement is at least a psychological barrier to receipt of hospice care, they were unsure about what criteria should replace it. Two observers thought that when patients are very sick with "a clinical diagnosis of an eventually fatal illness" they should be eligible for palliative care. However, it would be difficult to operationalize this concept and it would not address the difficulty of getting people to accept receiving care related to their impending deaths.

Benefits

Medicaid hospice programs must offer at least the same services as Medicare—nursing care; medical social services; physician services; short-term inpatient services (for pain control or acute or chronic symptom management and for providing respite for family members); homemaker services; counseling services; home health aide; medical appliances and supplies (including drugs and biologicals); physical and occupational therapy; speech-language pathology services; and bereavement counseling (State Medicaid Manual Part 4, section 4305). Medicare and Medicaid also will pay for treatments by other health care providers for conditions not related to the terminal illness. For example, a nursing home resident in hospice because of cancer could get treatment for a fractured hip.

Although Medicaid and Medicare hospice benefits are almost identical, state Medicaid programs have certain other obligations and options when the programs cover hospice services. Medicaid programs cannot impose copayments on hospice patients, and the programs must pay Medicare hospice copayments for dually eligible beneficiaries. In addition, Medicaid can cover other Medicaid services that are related to the treatment of terminal illness as long as these services "would not be covered under the Medicare hospice program" (Health Care Financing Administration, 2000). For example, if a state covers the optional personal care service, its Medicaid program can cover personal care for hospice patients who have no primary caregiver available.

As in Medicare, Medicaid hospice care is classified into four different categories, depending on how much care is needed (State Medicaid Manual, Part 4, section 4305.7). First,



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Some Medicaid programs' coverage of pain-relief measures can also limit patient access to needed care.

“routine home care” encompasses services that patients need on a day-to-day basis. Second, “continuous home care” is available during crises and is defined as providing at least eight hours a day of mostly nursing care to manage acute medical symptoms. Third, “short-term, inpatient care” is inpatient care necessary for pain control or symptom management when procedures necessary for pain control or symptom management cannot feasibly be provided in other settings. Short-term inpatient care must be provided in an institution that meets hospice conditions of participation in Medicare and Medicaid. Fourth, “in-patient respite care” is available to relieve unpaid caregivers on an occasional basis for not more than five consecutive days. In general, all hospice services must be related to management, not cure, of a terminal illness or to maintain a person’s ability to perform daily activities.

There are certain problems with current Medicaid hospice benefits for dying beneficiaries that are similar to problems with Medicare’s benefit. People who elect hospice must forgo “curative treatment” for their terminal illness and sometimes the line between treatment and palliation is not clear-cut. For example, chemotherapy and radiation are normally curative treatments, but they can also provide pain relief when used to mitigate the effects of cancer in the end stage of illness. Separate payment for palliative services would help make these services available to people who might not want to give up “curative treatment” as they must when choosing hospice, but such payment could raise Medicaid program costs and the benefit could be difficult to control.

In addition, there are several issues related to prescription practices and drug coverage that could affect Medicaid beneficiaries, although they are not specifically Medicaid

policies. Opioids, the major class of analgesics used in management of moderate to severe pain (e.g., morphine), fall under each state’s controlled substances acts and are subject to certain restrictions that can make obtaining prescriptions difficult. In addition, since state medical boards often investigate prescriptions that exceed recommended dosage levels, patients needing high levels of pain medications may have difficulty getting prescriptions written. Moreover, pharmacies often have limited supplies of controlled substances or do not stock them at all, which can make obtaining pain-relief medications cumbersome at best.

Some Medicaid programs’ coverage of pain-relief measures can also limit patient access to needed care. The cost of some pain-control measures, such as chemotherapy or intravenous medications, are high and not all programs cover such options. Access to a wide range of opioids and pain-relief measures is important because many patients need strong measures while they are dying and the side effects can vary among patients. However, experts from some states said that Medicaid provisions did not present any problems, emphasizing the fact that Medicaid policies vary greatly across states.

The third major benefit issue is that, as of December 2000, some states are still requiring patients to give up certain services when they opt for hospice care, as federal Medicaid law required until 1990. The Omnibus Budget Reconciliation Act of 1990 (OBRA 90) eliminated the requirement that Medicaid hospice patients give up other Medicaid services (State Medicaid Manual, Part 4, section 4305). However, some states, such as New York, still require people receiving hospice to give up their Medicaid personal care services, creating another barrier to the use of the service.

Quality Assurance

Medicare and Medicaid have quality standards governing hospices and, in recent years, issues of pain management and provision of palliative care in nursing homes have drawn the attention of federal policymakers. For example, two studies document improved quality of life and pain management for nursing home residents receiving hospice care compared to residents receiving only routine nursing home care (Zerzan et al., 2000). However, education of providers about these issues, and the labor shortage among health care workers, especially in long-term care, has not received as much governmental attention.

To participate in Medicaid, hospices must meet Medicare's conditions of participation, which require that an interdisciplinary team supervise or deliver a defined set of services based on a written plan of care (Code of Federal Regulations, part 418, subparts C-F). In addition, hospices must have an internal quality assurance program and an employee directing volunteer activities. There are other requirements related to record keeping and delivery of services such as inpatient hospice care.

Nursing homes have a separate set of conditions of participation that they must meet to serve Medicare and Medicaid beneficiaries. These conditions and the associated survey and certification procedures require a plan of care for each nursing home resident and focus on rehabilitation and restoring nursing home residents' functioning (Zerzan et al, 2000). Two potential problems result from these rules and procedures. First, a nursing home resident who elects hospice will have two potentially competing plans of care, one from the hospice and the other from the nursing home. The hospice's plan of care likely would emphasize palliation while the nursing home's plan likely would emphasize rehabilitation and restoration.

Unless the nursing home and hospice coordinate their plans of care, the resident could be receiving care that is inappropriate.

The second problem is that Medicare and Medicaid's quality assurance system for nursing homes does not focus on palliation and appropriate care for dying residents. For example, the nursing home resident assessment instrument does not include "protocols for palliative care" and some of the symptoms of terminal illness such as weight loss are considered indicators of potential quality problems (Zerzan et al, 2000). Thus, the current system may not be doing all it could to promote appropriate care for dying residents or recognize the terminal phases of illness among nursing home residents.

The non-governmental experts' views were mixed regarding the role of Medicaid and Medicare in quality assurance. Most observers interviewed said that government should take a stronger role in assuring quality of care at the end-of-life, but a minority of experts argued that the government should not try to take on the issue. Advocates of greater government involvement said that experts in pain management and palliative care should examine Medicaid and Medicare survey and certification provisions for hospices, nursing homes, and hospitals, determine whether changes should be made, and develop an improved set of common provisions for Medicare and Medicaid related to end-of-life care. As a way of expanding access to these services, one expert suggested that hospitals be required to have contracts with hospices or to provide palliative services. Those opposing a strong governmental role in quality assurance contended that private-sector initiatives, such as educating providers, are the most effective route toward quality improvement.

HCFA has some efforts underway that could lead to improvements in end-of-life care, including a dialogue with the hospice industry about outcomes measures. First, the Outcomes Forum — an industry-funded consortium of chief executive officers of 15 or more major hospices, whose mission is to develop outcome measures for hospice care — includes a HCFA staff person.

Second, HCFA has contractors working to improve measurement of pain in the nursing facility minimum data set (MDS), which is the resident assessment instrument that facilities must use for Medicare and Medicaid patients. HCFA is also considering development of new quality indicators for nursing homes that would relate to proper pain assessment and treatment. Guidance is being developed for surveyors to help them recognize the end-of-life among nursing home residents and to help ensure that nursing homes deliver appropriate care to dying residents.

Third, HCFA recently awarded grants to enable five states to develop Programs of All Inclusive Care for Children (PACC), which will coordinate and integrate all health, social, and supportive services for children with life-threatening conditions and their families, with the goal of improving quality of care for dying children. In September 2000, five states—Florida, Kentucky, New York, Utah, and Virginia—received one-year grants of approximately \$250,000 each to develop these programs.

Presently, federal and state Medicaid programs are doing relatively little to educate providers or beneficiaries about end-of-life care or about the availability of hospice. Of particular concern is that Medicaid and Medicare requirements related to training of

health staff, such as certified nurse assistants in nursing homes, do not address pain management and palliative care. However, one expert cautioned that educating nursing home staff will not have much effect unless the survey and certification processes focus on measuring palliative services and pain management, and payers (including Medicaid) recognize palliation as a separate, reimbursable nursing home service.

A final quality issue is the shortage of workers, due to low unemployment, low wages and benefits, and difficult working conditions. On the one hand, non-governmental experts say that hospices appear not to be experiencing labor shortages to the degree nursing home and home care providers are. On the other hand, nursing homes and home care agencies have high turnover rates, which experts say could affect long-term care workers' preparation for caring for people at the end-of-life.

Payment

Unlike almost all other Medicaid services (including nursing homes and home care) where states have almost complete flexibility in how they set payment rates, states must pay hospices at least federally set, minimum rates. States, however, can increase the payment rates (State Medicaid Manual, Part 4, section 4306). State Medicaid programs are supposed to pay hospices one of four prospective rates depending on the level of care provided—routine home care at \$101.97 a day, continuous home care at \$594.64 a day, inpatient respite care at \$110.89 a day, or general inpatient care at \$453.04 a day. These rates are adjusted for regional wage differences. Starting in April 2001, the Medicare and Medicaid hospice rates will be increased by five percent as mandated by BIPA of 2000.

There are two additional ways in which states can control Medicaid hospice payments. First, states can place a cap on aggregate Medicaid payments to each hospice if they choose (State Medicaid Manual, Part 4, section 4308). The aggregate cap is calculated by multiplying the number of Medicaid beneficiaries served by an individual hospice by a “cap amount” — \$15,916.98 effective November 1, 1999-October 31, 2000. Hospices with Medicaid expenditures exceeding the cap amount must refund any payments received in excess of the cap. Second, an individual hospice’s aggregate number of inpatient hospice days during a fiscal year may not exceed 20 percent of the total days of care the hospice provides to all Medicaid beneficiaries (State Medicaid Manual, Part 4, section 4306.5). However, states may choose to exclude Medicaid beneficiaries with AIDS when calculating the aggregate limit on an individual hospice’s total inpatient days. The hospice must refund any excess Medicaid reimbursement.

There are at least three major payment issues. First, according to most non-governmental experts, the current hospice rate for routine home care is too low to enable hospices to provide the most advanced types of pain relief, such as chemotherapy and radiation treatments. Another reason the payment level is considered low is that hospices tend to serve patients in the last few weeks before death when care can be particularly expensive and the payment rates do not adequately adjust for casemix. These experts did not assert that the other three categories of hospice rates are too low.

Second, payment rates are based on very old cost experience that no longer reflects current expenses. Data from hospice demonstration projects conducted during the early 1980s were used to calculate the initial Medicare hospice

rates, upon which both current Medicare and Medicaid rates are based. Since implementation of the Medicare and Medicaid hospice benefits, payment levels have been updated periodically by the hospital market basket (i.e., a measure of the hospital inflation) minus a small percentage that Congress determines each year. At the request of the industry, hospices began submitting cost reports to HCFA in April 1999 in the hope that these data might be used to determine the adequacy of hospice payment rates.

Third, the way in which Medicaid pays nursing homes for hospice patients causes a great deal of confusion. In these circumstances, the hospice is the primary caregiver for the resident and the nursing home supplies room and board, which is defined in the State Medicaid Manual (section 4308.2) to include help with activities of daily living, medication management, supervision, cleaning a person’s room, and prescribed therapies. State Medicaid programs must pay at least 95 percent of the nursing home rate for room and board directly to the hospice, which in turn pays the nursing home.

Several problems result from this payment system. Reportedly, nursing homes rarely accept less than 100 percent of the Medicaid room and board payment. As a result, hospices generally pay full room and board costs, which means that they suffer a financial loss. In addition, the nursing home’s payment can be disrupted or payment to the hospice can be delayed when the Medicaid program switches from paying the nursing home for people who are already residents to paying the hospice. Finally, it is not clear who should collect the spend down payments (i.e., the contributions toward the cost of care) that medically needy and other nursing home residents pay when they are on Medicaid. Having states pay nursing homes directly for the



Several problems result from this payment system. Reportedly, nursing homes rarely accept less than 100 percent of the Medicaid room and board payment.

room and board of hospice patients would alleviate confusion and aid the finances of hospices, but to the detriment of nursing homes.

Case Studies

Experts in end-of-life care were asked to nominate states or health care systems that are innovative in delivering end-of-life care to Medicaid beneficiaries. Experts did not nominate any states, but suggested four health care systems. Three of these health systems—the Community Medical Alliance (CMA), On Lok, and EverCare—are managed care plans which receive capitated payments for serving a predominantly Medicaid population. These providers integrate health, long-term and end-of-life care using an interdisciplinary team approach to management of an enrollee's services. Thus, unlike the fee-for-service system or other managed care plans, CMA, On Lok, and EverCare use an integrated system of care that does not require enrollees and their families to navigate a complex health system on their own. The fourth provider nominated for its innovation was the Florida Hospice of the Suncoast. It is an example of a hospice that is taking the initiative to provide palliative services to Medicaid beneficiaries of all ages who do not want or are not ready for hospice. Each of the following case studies describes how the providers deliver services, assure quality, and are paid for care. *Chart 1* compares key aspects of these providers' systems. Web sites related to these systems are included in the references.

Community Medical Alliance

The Community Medical Alliance (CMA), a subsidiary of Neighborhood Health Plans (NHP), is a Boston-based health care system that contracts with the Massachusetts Medicaid program to provide comprehensive benefits to Medicaid beneficiaries with advanced AIDS and

individuals with severe disabilities, such as muscular dystrophy, in return for capitated payment. In 2000, CMA started a program for technology-dependent children. CMA provides services through primary care practices in Boston.

In 1992, CMA started with a pilot project of 100 Medicaid enrollees with severe disabilities and about 50 patients with advanced AIDS. By 2000, CMA had about 500 enrollees in Boston, of whom 125 were dually eligible for Medicare and Medicaid; about 240 patients had AIDS, 260 had severe disabilities, and 30 were children. The program expanded throughout Massachusetts to Springfield in 1998, Worcester in 2000, and New Bedford in 2001.

In CMA, teams of physicians and nurse practitioners manage services for beneficiaries. Physicians and nurse practitioners have virtually complete authority to admit patients to the hospital, refer them to specialists, or allocate resources within the network to meet enrollee needs without risking financial penalties or having to obtain prior authorization (Master, 1998). The parent plan—NHP—has internal management and information technology systems to carry out the primary care team's orders.

Primary care physicians are usually salaried and most practice in NHP's network of community health centers, while nurse practitioners are employees of CMA. Nurse practitioners are the primary contact point for enrollees, who average two to three visits or telephone calls a month from the practitioners. Enrollees with emergency needs also have access to nurse practitioners 24 hours a day, seven days a week. Caseloads are 25 for nurse practitioners serving AIDS patients, and 45 for those serving enrollees with severe disabilities.



In 1992, CMA started with a pilot project of 100 Medicaid enrollees with severe disabilities and about 50 patients with advanced AIDS.

CMA enrollees receive all Medicaid benefits, including a broad range of services needed at the end-of-life. The primary care team develops an individualized care plan in consultation with the enrollee. The team does not have formal discussions with new enrollees about their preferences regarding end-of-life care. Rather, these discussions occur over time as the team develops relationships with enrollees and care plans follow patients' wishes regarding the dying process. Some patients want emergency hospitalization and 24-hour ventilators, while others do not want to be hospitalized. Staff has found that patient wishes can also evolve over time, particularly among AIDS patients whose conditions may improve as a result of drug treatments.

CMA does not have a separate palliative care service because this form of care is integrated into ongoing services. Enrollees have access to personal care, pain management, social work and counseling, private duty nursing, psychiatric nursing, and needed drugs. Although spiritual counseling is not routine, the health plan will arrange for it at the enrollee's request.

CMA assures the quality of its services by recruiting nurse practitioners who have experience serving with the health plan's populations. The programs serving those with AIDS and severe disabilities each have a physician medical director, who oversees all aspects of the clinical program, and a nurse practitioner director who oversees the work of the nurse practitioners. Nurse practitioners also train aides on how to serve enrollees, in skills like proper transfer techniques. Health and long-term care labor force shortages have not affected CMA to any great degree, at least in regard to nurse practitioners.

CMA also assures quality by comparing its utilization and cost data to benchmarks, such as hospital admissions, and frequency of contacts with enrollees, incidence of decubitus ulcers, and immune system functioning in the AIDS population. Patients also have grievance procedures they can use.

CMA says it receives an "adequate" negotiated, capitated payment from the Massachusetts Medicaid program. When the project first began in 1992, the rate reflected fee-for-service experience with the AIDS and severe disabilities populations. Now, CMA negotiates its rates annually with the state, based on costs incurred during the previous fiscal year. In fiscal year 2001, CMA receives \$2,564 per member per month for enrollees with AIDS and severe disabilities. The rate for technology-dependent children is \$8,000 per member per month, and \$3,200 for high risk children and adolescents with major behavioral health problems.

On Lok

On Lok is a non-profit managed care plan that provides medical and long-term care to frail older persons who reside in the community but who are eligible for nursing home coverage. The program began in 1971 in San Francisco, California, by providing adult day health care. The range of services expanded over time and the plan obtained waivers from Medicare and Medicaid in 1983 to provide a comprehensive range of health and long-term care services to frail nursing home eligible enrollees under risk-based, capitated reimbursement. Services that enrollees receive include: assessment, care planning, primary care, comfort care, counseling, therapies, meals, activity programs, personal care, and transportation. On Lok contracts with other providers such as hospitals

and pharmacies for the medical services they do not provide directly. On Lok's waivers became permanent in 1986. In 2000, the plan served 860 enrollees—whom approximately 90 percent were Medicaid eligible—at five sites in San Francisco.

In an effort to test the On Lok model, 25 similar organizations in 13 states, called Programs of All Inclusive Care for the Elderly (PACE), have been established with an average daily census of 6,045 enrollees (National PACE Association, 2000). An additional 70 PACE programs are in various stages of development in 30 states. Beyond the 13 states where PACE is currently operating, another eight states have included PACE as an optional service under their Medicaid programs, but as yet have no provider agreements in place (Health Care Financing Administration, 2001).

On Lok's enrollees must be at least 55 years old and certified by California's Medicaid program as needing care in a nursing facility. On Lok patients are medically frail with such conditions as congestive heart failure or renal failure, or are physically dependent. Seventy percent of deaths at On Lok are due to chronic illness and about half of these deaths are due to dementia.

Each enrollee's care is planned and managed by an interdisciplinary team composed of physicians, nurses, social workers, therapists, dietitians, and transportation and home care workers. The team assesses each enrollee's needs upon enrollment and at least every three months thereafter.

Assessments include rankings on a pain scale. Pain assessment for persons with dementia requires judging whether clients are losing weight, exhibiting distress, and other sorts of behavioral symptoms. In addition, dementia

patients are shown a chart of faces with differing expressions of discomfort or pain and are asked to pick the one that resembles how they feel. The focus on pain assessment began in 1997 when On Lok started its initiative to improve end-of-life care (On Lok, 2000). The initiative consisted of one year internal training for plan staff that focused on improving end-of-life care, particularly services related to pain and symptom management and psychological support.

Within six months of entering On Lok, the primary care staff (a physician or nurse practitioner) on the team must initiate a discussion of the client's desires regarding end-of-life care, including preferences about resuscitation, feeding tubes, and aggressive medical procedures; more than 90 percent of enrollees have advanced directives. Spiritual needs are addressed by asking enrollees what they think about death and the dying process so that the team can provide appropriate counseling and services. Should patients' conditions or preferences change over time, the team will modify service delivery and advanced directives.

On average, On Lok enrollees receive care from the plan during their last four years of life. For those who are at the end-of-life due to conditions such as heart disease, length of enrollment at On Lok ranges from six months to two years. Those who are dying because of dementia or functional impairment receive services for four or more years, on average. At any given time, seven percent of enrollees are dying. When this occurs, On Lok does not refer patients to hospice, but rather provides comfort care, including pain management, until death. Dying patients receive comfort care for 163 days on average—almost three times the number of days provided before On Lok's 1997 end-of-life initiative.

Giving social workers lead responsibility for helping to meet patient and family psychosocial needs is also part of On Lok's comfort care. Staff tries to prepare families so they will not be surprised by an enrollee's death. Families are kept abreast of the patient's condition and provided counseling when necessary.

Social workers and other staff must also deal with problems that certain enrollees face in finding or keeping a place to live while dying. When people are dying in residential settings—such as assisted living facilities, single room occupancy dwellings, or board and care homes—these facilities sometimes force residents to leave because they cannot or do not want to deal with a dying resident. Due to high housing costs in the San Francisco area, it is very hard to find replacement housing. Equally problematic has been the general labor shortage among long-term care workers. On Lok has difficulty recruiting nurses and in-home workers. The nursing homes that contract with On Lok are facing similar problems.

To assure quality in end-of-life care for its enrollees, On Lok conducts an annual analysis of deaths that focuses on patient age and location of death, cause of death, determination of whether a comfort care plan was in place, duration of comfort care, and use of services in the last month of life. The performance of the interdisciplinary teams are compared, and any team with problems receives education about how to improve service delivery.

On Lok receives capitated payments from Medicare and Medicaid that cover the costs of all medical and long-term care services that an enrollee needs. The capitation rate from Medicare is 2.39 times the adjusted average per capita cost (AAPCC) for Medicare beneficiaries in On Lok's service area. In 2000, the Medicare

payment was \$1,350 per month per enrollee and the capitation rate that On Lok negotiated with the state Medi-Cal program was \$2,650 per month. The state rate is calculated based on 90 percent of what the state pays for a nursing home resident in the San Francisco Bay area. Prior to 2000, the rate was 85 percent of the nursing home rate, but was increased to 90 percent of that rate in recognition of the increasing cost of labor in the Bay Area.

EverCare

EverCare, a subsidiary of United HealthCare Corporation, is a Medicare managed care plan that provides preventive and primary care to residents of nursing homes and assisted living facilities through nurse practitioner and physician teams (United HealthCare, 2000). Started in Minnesota in 1987, the plan serves a total of 20,000 enrollees with additional sites in Arizona, Colorado, Georgia, Florida, Maryland, Massachusetts, New York, and Ohio.

The Minnesota site serves Medicare beneficiaries who are eligible for parts A and B, 70 percent of whom are also eligible for Medicaid. EverCare's goal is to provide good quality geriatric care to residents in their facilities. Interdisciplinary teams composed of physicians and nurse practitioners provide primary care services, including orders for laboratory tests, intravenous therapy, and other medical procedures. Like most other Medicare managed care plans, enrollees in EverCare do not have to pay the 20 percent coinsurance that Medicare requires for physician and other Part B services.

The nurse practitioner plays a key role in providing services and is the focal point of communication for facility staff, residents, and family members. The nurse practitioners visit



On Lok receives capitated payments from Medicare and Medicaid that cover the costs of all medical and long-term care services that an enrollee needs.

residents in the facilities at least monthly, with some residents receiving more frequent contact when their conditions warrant it. Typically, nurse practitioner visits occur two to three times a week when patients are dying. Physicians visit residents jointly with the nurse practitioner every 120 days and more frequently if the condition of the patient changes.

Shortly after enrollees join EverCare, nurse practitioners discuss quality of life and end-of-life issues with residents and family members to determine an appropriate plan of care. EverCare provides palliative services that are integrated into the primary care-delivery system and the nurse practitioners are required to have skills in pain management, hydration, comfort care, and other end-of-life services. EverCare refers residents to hospice when the member would benefit from such services as bereavement counseling. Under hospice, EverCare continues to provide all primary care services to enrollees.

Quality assurance for EverCare depends heavily on the recruitment and training of nurse practitioners. Before final hiring decisions are made, practitioners spend half a day in a facility to make sure they are comfortable with the culture of the nursing home and serving frail, older residents. EverCare mostly hires experienced nurses who are new nurse practitioners. Each new hire receives an intensive, six-month orientation program. Thus, the nurse practitioners receive training about the plan's approach to delivering primary care in nursing homes. Continuing education occurs monthly through in-service programs. Nurse practitioners do not have full caseloads, which average less than 100 residents, until six to nine months after being hired. Nurse practitioners are on teams led by a clinical services manager who is a nurse

practitioner trained in the EverCare model. The manager has daily contact with new nurse practitioners.

EverCare also has a clinical quality committee that meets monthly to discuss quality issues and progress with the plan's initiatives to improve quality for enrollees, such as trying to increase vaccination rates among enrollees, promoting use of advance directives, and tracking sentinel events such as unexpected deaths associated with changes in medication. Each site reports on its progress in addressing these initiatives to EverCare's local and corporate quality councils. EverCare interacts with nursing home staff by developing programs that teach quality indicators and how to prevent adverse events. The plan also works with nursing home staff to coordinate efforts to deal with quality problems such as dehydration.

EverCare receives capitated payments from Medicare and is at risk for all Medicare services, except for hospice. From Medicare, EverCare receives AAPCC minus 5 percent, which is the routine payment to health maintenance organizations. For dually eligible residents, Minnesota's EverCare site is at risk for all Medicaid benefits that Medicare does not cover, with the exception of nursing home daily care. Minnesota's Medicaid capitated payment rate for EverCare is age and sex adjusted.

Hospice of the Florida Suncoast

The 20-year-old Hospice of the Florida Suncoast is a non-profit provider founded by volunteers that serves more than 1,200 patients a day in Pinellas County, Florida (National Coalition on Health Care and Institute for Healthcare Improvement, 2000). The hospice offers a comprehensive program of



EverCare receives capitated payments from Medicare and is at risk for all Medicare services, except for hospice.

medical and palliative care, which includes counseling, spiritual support and other services such as home health. The hospice has 850 staff and more than 2,800 volunteers who help provide services.

The hospice serves three categories of Medicaid beneficiaries—dying children and adults, AIDS patients, and Medicare and Medicaid dually eligible nursing home residents. The hospice has a child and family support program that served more than 2,000 families in 1999, with about 10 children a day covered by Medicaid. The program helps families caring for dying children and those who have recently experienced a death. Thirty patients a day or 75 percent of the hospice's AIDS patients who are receiving home health services from the hospice are Medicaid eligible. Two hundred patients a day or 50 percent of the nursing home residents the hospice serves are dually eligible for Medicare and Medicaid. Forty-nine patients a day or 70 percent of patients receiving home health services from the hospice are on Medicaid. About 8 percent of the hospice's revenue comes from Medicaid.

Half of the referrals to hospice come from physicians and the rest from hospital or community case managers and self-referrals. The proportion of patients who self-refer has increased over the last several years, perhaps because consumers are becoming more proactive about managing their own health care services.

The hospice does not view the six-month prognosis requirement of the Medicare and Medicaid hospice benefit as a significant barrier to serving patients because it has been able to meet the requirement with careful documentation of the patient's condition. Hospice staff can produce this documentation

because they are trained to paint a comprehensive picture of the patient and family, describing psychological, social, and spiritual issues, which will likely contribute to a shortened prognosis, in addition to documenting the clinical indicators of progression of illness. The average length of stay at this hospice is 98 days compared to about 48 days nationally, so the hospice is treating people earlier in the process of dying than most other providers (NHCP0, 2000).

For those who have prognoses of longer than six months or who do not want to waive curative services, the hospice offers an array of palliative services, including counseling and pain management. Even though Medicaid does not cover palliative care, per se, hospice physicians and nurses receive Medicaid reimbursement for medical management of palliative care. With appropriate documentation, Florida Medicaid also covers most drugs that patients need for pain relief. However, in order to pay for supplies and services that Florida Medicaid does not cover, an organizational affiliate of the hospice — AIDS Services of Pinellas County — conducts community fundraisers.

Nursing home residents receive hospice care from four teams that are devoted exclusively to this population. These teams try to develop good working relationships with nursing home staff to help mitigate the coordination problems that can occur between the nursing home and hospice.

The hospice's mission includes a number of educational endeavors which involve educating staff and the community about end-of-life issues (The Hospice of the Florida Suncoast, 2000). New physicians, nurse practitioners, staff, and volunteers receive an intensive

training program when they join the hospice. Medical, nursing, and social work students rotate through the hospice as part of their training. The Hospice Institute of the Florida Suncoast offers education and training sessions for staff and volunteers and develops model care programs that it disseminates to other hospices. For example, in 2000, the Hospice of the Florida Suncoast partnered with other hospices and health care providers to provide advance-directive packets to hospitals, clinics, malls, community associations, and schools for distribution to the general public. A follow-up activity was a series of town hall meetings held in Pinellas County on end-of-life issues and caregiving.

The Hospice of the Florida Suncoast operates a quality management program, which has four staff persons. The program audits service delivery, tracks patient and family complaints, and conducts consumer satisfaction surveys. Each of the hospice's four regional offices in Pinellas County has a quality assurance program tailored to the local results on these measures.

Staff turnover at the hospice is reported to be approximately 5 percent a year, although recruiting aides and counselors is starting to become somewhat difficult because of the labor shortage. Hospice staff attributes their success in recruiting and retaining employees to the non-profit nature of the organization, the fact that staff is doing meaningful work, and that the hospice takes care of its staff through training and creation of a supportive work environment.

The hospice contends that Medicaid payments are not sufficient to cover the rates that the hospice pays its staff and providers. For example, Medicaid reimbursement for nursing visits in the home health, AIDS home and

community-based services waiver program is about \$27 an hour. Reimbursement for home health aide visits is \$10 an hour, reportedly less than one-third of what it costs the hospice to provide these services. Likewise, Medicaid physician reimbursement is far below what the organization pays and the hospice also reimburses nursing homes 100 percent of room and board costs, while Medicaid only pays them 95 percent of the costs. The Hospice Foundation of the Florida Suncoast helps fund deficits and charitable care by seeking memorial donations, encouraging planned giving, and arranging fundraising events.

Conclusion

Federal and state Medicaid policy on end-of-life care revolves around the program's hospice benefit, which closely resembles the Medicare benefit. Medicare's benefit was designed primarily to accommodate an older person dying of cancer at home with family caregivers available. While some of the Medicaid population fits this description, many who need end-of-life care do not, such as those who have chronic illnesses with major long-term care needs. In addition, dying children have special needs and family circumstances that adults do not.

Federal and state Medicaid programs are only beginning to attend to the role the program plays as one of the largest governmental programs financing care for people during their last year of life—a role that reaches far beyond the hospice benefit. The overwhelming part that Medicaid plays in financing nursing home and other forms of long-term care is particularly important. On the positive side, the Health Care Financing Administration (HCFA) has several efforts underway to address pain management in nursing homes. However, other

than a few small efforts, Medicaid is not focusing in a major way on using its market power to encourage or force changes that would increase Medicaid beneficiaries' access to quality palliative services at the end-of-life. Thus, we have virtually no state Medicaid programs to point to as models in delivery of end-of-life care.

A five-part strategy on the part of federal and state officials, providers, and foundations could help improve quality of care for dying Medicaid beneficiaries. First, a re-examination of federal and state policy is difficult without better data about Medicaid beneficiaries and their experiences while dying. Compared to a modestly rich research literature on end-of-life care for Medicare, virtually no data or research has been conducted on end-of-life care for Medicaid beneficiaries (Scitovsky, 1994). One extant study on this topic is over a decade old and only dealt with the dually eligible population age 65 and older in one county in New York state (Temkin-Greener, et al, 1992). The other study focuses on Medicare beneficiaries who are dually eligible (Hogan, et al, 2000). The data needed include information on causes of Medicaid beneficiaries' death, location of death, and utilization and cost of services during the last year of life, and how these compare to non-Medicaid decedents. These data would help policymakers focus on where and when deaths occur and whether beneficiaries receive sufficient access to hospice and palliative services.

Second, Medicaid could consciously encourage or require the health systems with which it contracts to pay more attention to end-of-life care. A few health systems, especially some managed care plans, are using Medicaid funds in innovative ways to care for dying Medicaid beneficiaries. The Community Medical Alliance, On Lok, and EverCare are examples of new approaches to financing and delivering Medicaid end-of-life care. These organizations have used the flexibility of capitation payments to provide needed services without reference to whether they fit specific fee-for-service categories.² These plans integrate palliative and hospice care into their health care-delivery systems through the use of interdisciplinary teams. Obviously, dependence on managed care raises issues of freedom-of-choice of providers and capitation provides incentives for underservice, but this approach also gives plans the ability to use their funds in creative ways.³

Third, federal and state Medicaid officials could explore ways to fund palliative care and make a range of pain relief measures available through the fee-for-service system. Despite the efforts of the providers profiled in the case studies, provision of palliative services, such as pain management and psycho-social services, to dying patients outside of the hospice benefit appears to be limited. In a striking exception, the Florida Hospice of the Suncoast has used the current Medicaid coverage of physician, and nurse practitioner services as well as drug benefits to provide some palliative services to Medicaid beneficiaries outside of the Medicaid



The Community Medical Alliance, On Lok, and EverCare are examples of new approaches to financing and delivering Medicaid end-of-life care.

²The new Medicaid managed care organization regulations issued at the end of the Clinton administration clarify that these organizations may cover "services that are in addition to those covered under the state plan" (42 CFR 438.6(e) as published in the Federal Register, January 19, 2001, p. 6406). The Bush Administration has put these regulations on hold.

³However, capitation and managed care can also reduce integration. For example, state Medicaid provisions related to outpatient drug coverage could affect the flexibility that managed care organizations and hospices have to provide palliative care to dying beneficiaries. States that "carve out" pharmaceutical benefits and pay a capitated rate to pharmaceutical benefit management companies could create coordination problems between a managed care plan trying to provide pain-relief medications and the management company.

benefit. Experts persistently identified lack of explicit Medicaid coverage of palliative care to be a major funding problem. However, it is not clear how best to provide palliative care while addressing the need to restrain expenditure increases.

Fourth, beyond reimbursement for palliative care, efforts to better monitor pain management and end-of-life care in nursing homes and home care represents an attractive opportunity for improvement. Medicaid could use its overwhelming role in financing long-term care services to promote better care for dying beneficiaries by examining its current policies and modifying them to require participating providers to do such things as measure and control pain.

Fifth, the current structure of the Medicaid hospice benefit should be re-examined. The six-month prognosis requirement, inadequate payment rates, and the need for quality assurance systems to address palliation and pain management in new ways were all identified as problem areas. Currently, no consensus exists about how best to address these issues. However, the cost data that HCFA is now collecting from hospices and its discussions about outcomes measures with providers should help shed some light on how future progress can be made in these areas. Linking eligibility for hospice to diagnosis of a potentially fatal illness would help expand palliative care services, but containing expenditure increases could be difficult.

The challenge for the future will be to harness the Medicaid's purchasing power to improve the services that dying beneficiaries receive. Up to now, Medicaid has been the sleeping giant of end-of-life financing.

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Table 1—Medicaid Expenditures for Hospice, FFY 1990-1998

State	1990	1991	1992	1993	1994	1995	1996	1997	1998
United States	\$20,231,587	\$44,092,149	\$84,184,532	\$128,896,473	\$197,631,713	\$288,619,978	\$322,401,343	\$327,263,161	\$325,010,325
Alabama	0	169,185	552,150	772,901	1,117,145	2,358,176	3,233,392	5,099,842	5,361,330
Alaska	0	0	0	0	0	0	24,380	52,406	75,360
Arizona	0	0	0	0	16,962	1,517	0	0	0
Arkansas	0	0	0	0	0	0	1,637,723	2,079,369	3,178,795
California	1,398,370	3,618,095	6,838,205	14,001,850	26,023,740	35,009,849	38,957,683	37,931,368	32,427,902
Colorado	0	4,331	713,453	1,082,110	2,097,770	4,166,119	5,255,714	4,821,100	5,257,849
Connecticut	0	0	0	0	0	0	0	0	0
Delaware	0	0	255,772	240,433	576,695	622,494	1,046,103	777,750	681,498
District of Columbia	0	0	0	0	0	0	0	0	0
Florida	8,078,319	20,303,012	30,994,185	40,776,343	43,647,375	56,099,375	55,301,090	49,315,483	48,444,311
Georgia	467,921	608,060	1,033,174	2,086,947	3,301,172	6,680,883	9,134,598	15,138,611	17,379,632
Hawaii	0	0	27,581	177,609	388,536	267,322	303,896	460,416	420,326
Idaho	76,290	55,594	63,769	109,103	163,857	403,352	428,939	391,414	537,068
Illinois	853,898	2,518,935	6,167,618	6,193,764	13,349,735	24,672,877	23,976,984	21,650,973	18,747,727
Indiana	0	0	0	0	0	0	0	0	(4,350)
Iowa	10,973	401,032	795,072	755,592	1,358,698	2,216,997	2,191,623	1,074,526	2,802,567
Kansas	0	187,646	609,043	981,663	1,967,346	2,056,915	2,197,811	2,270,140	2,458,179
Kentucky	1,940,174	3,219,287	4,777,566	6,883,160	9,664,931	10,802,515	9,131,287	9,754,700	7,561,272
Louisiana	0	0	0	0	89,272	247,483	903,012	1,160,070	1,819,083
Maine	0	0	0	0	0	0	0	0	0
Maryland	0	0	0	0	50,200	348,444	1,684,069	5,023,339	2,684,618
Massachusetts	589,785	1,462,871	3,095,835	4,684,834	7,289,974	9,890,240	9,745,063	8,652,782	8,053,232
Michigan	825,920	741,899	3,428,852	5,946,512	9,413,119	11,785,677	12,541,392	12,674,953	13,336,548
Minnesota	14,869	256,040	321,151	769,686	1,438,668	5,088,645	5,255,079	4,194,017	4,897,304
Mississippi	0	0	264,071	608,144	1,035,217	2,355,900	2,365,662	3,364,968	4,310,316
Missouri	265,472	747,061	1,360,694	2,434,166	3,801,809	7,185,140	9,268,005	10,069,300	8,668,745
Montana	72,329	65,861	172,482	225,433	337,384	300,408	322,534	246,039	291,534

Source : Urban Institute Estimates based on HCFA-64 data.

Table 1 (continued) Medicaid Expenditures for Hospice, FFY 1990-1998

State	1990	1991	1992	1993	1994	1995	1996	1997	1998
United States	\$20,231,587	\$44,092,149	\$84,184,532	\$128,896,473	\$197,631,713	\$288,619,978	\$322,401,343	\$327,263,161	\$325,010,325
Nebraska	0	0	0	0	107,982	304,685	343,877	880,187	1,386,581
Nevada	0	0	0	0	0	0	0	0	259,542
New Hampshire	0	0	0	0	0	0	0	0	0
New Jersey	0	0	0	671,159	1,530,741	3,344,081	5,421,997	7,613,769	8,884,247
New Mexico	68,441	71,940	413,276	475,400	973,960	1,470,059	1,750,225	1,639,135	1,489,245
New York	1,433,277	1,925,341	3,107,857	5,606,357	9,480,348	18,951,600	23,772,786	24,167,426	25,327,772
North Carolina	1,196,953	1,557,656	3,305,005	7,465,301	11,021,340	10,553,011	10,603,426	10,600,677	8,372,635
North Dakota	0	0	0	104,443	458,611	547,917	456,567	847,326	854,296
Ohio	0	703,116	2,067,988	3,964,952	7,806,457	12,560,207	18,482,765	21,665,301	19,215,540
Oklahoma	0	0	0	0	0	0	0	0	0
Oregon	0	0	0	0	0	5,234	943,391	580,208	309,661
Pennsylvania	232,151	309,073	651,481	1,287,030	1,591,582	3,708,633	5,097,749	4,857,197	3,865,069
Rhode Island	26,369	66,582	30,158	75,147	110,527	279,709	671,859	1,236,172	993,035
South Carolina	0	0	0	0	0	0	1,536,063	2,683,673	2,524,920
South Dakota	0	0	19,301	73,594	96,387	89,358	104,872	142,096	106,840
Tennessee	0	0	950,132	1,607,636	984,475	93,156	6,357	0	572
Texas	2,663,675	4,714,712	11,117,601	16,289,989	29,796,702	40,447,414	43,085,272	42,659,247	47,608,566
Utah	0	0	17,574	40,850	706,862	4,187,344	3,670,200	(446,609)	767,945
Vermont	16,401	39,527	65,099	90,799	151,088	143,712	171,519	282,280	334,720
Virginia	0	57,673	310,854	603,822	996,131	1,529,465	2,281,166	2,669,192	3,151,736
Washington	0	0	0	424,623	2,838,245	4,379,579	4,816,626	4,317,976	4,543,237
West Virginia	0	0	0	0	0	693,114	1,021,349	887,651	1,051,787
Wisconsin	0	287,620	657,533	1,385,121	1,850,670	2,772,372	3,202,570	3,579,380	4,406,413
Wyoming	0	0	0	0	0	0	54,668	197,311	165,120

Source: Urban Institute estimates based on HCFA-64 data.

**Table 2—
Various Per Capita Measures of Medicaid Expenditures
for Hospice, FFY 1998 (using HCFA-64 expenditures)**

State	Hospice Patients (HCFA-2082)	Spending Per Patient	Spending Per Person
United States	51,722	\$6,284	\$1.20
Alabama	755	\$7,101	\$1.23
Alaska	11	\$6,851	\$0.12
Arizona	4	N/A	N/A
Arkansas	551	\$5,769	\$1.25
California	6,122	\$5,297	\$0.99
Colorado	1,232	\$4,268	\$1.32
Connecticut	46	N/A	N/A
Delaware	120	\$5,679	\$0.92
District of Columbia	96	N/A	N/A
Florida	7,583	\$6,389	\$3.25
Georgia	2,885	\$6,024	\$2.28
Hawaii	0	N/A	\$0.35
Idaho	116	\$4,630	\$0.44
Illinois	1,659	\$11,301	\$1.55
Indiana	378	N/A	N/A
Iowa	614	\$4,564	\$0.98
Kansas	579	\$4,246	\$0.93
Kentucky	1,629	\$4,642	\$1.92
Louisiana	588	\$3,094	\$0.42
Maine	0	N/A	N/A
Maryland	561	\$4,785	\$0.52
Massachusetts	1,754	\$4,591	\$1.31
Michigan	740	\$18,022	\$1.36
Minnesota	875	\$5,597	\$1.04
Mississippi	449	\$9,600	\$1.57
Missouri	2,049	\$4,231	\$1.59
Montana	0	N/A	\$0.33

Source: Urban Institute estimates based on data from HCFA-2082 and HCFA-64 reports and July 1998 population estimates from the Population Estimates Program, Population Division, U.S. Census Bureau.

**Table 2 (continued)—
Various Per Capita Measures of Medicaid Expenditures
for Hospice, FFY 1998 (using HCFA-64 expenditures)**

State	Hospice Patients (HCFA-2082)	Spending Per Patient	Spending Per Person
United States	51,722	\$6,284	\$1.20
Nebraska	N/A	N/A	\$0.83
Nevada	55	\$4,719	\$0.15
New Hampshire	0	N/A	N/A
New Jersey	1,471	\$6,040	\$1.10
New Mexico	277	\$5,376	\$0.86
New York	3,465	\$7,310	\$1.39
North Carolina	1,508	\$5,552	\$1.11
North Dakota	175	\$4,882	\$1.34
Ohio	3,401	\$5,650	\$1.71
Oklahoma	N/A	N/A	N/A
Oregon	83	\$3,731	\$0.09
Pennsylvania	654	\$5,910	\$0.32
Rhode Island	229	\$4,336	\$1.01
South Carolina	445	\$5,674	\$0.66
South Dakota	0	N/A	\$0.15
Tennessee	0	N/A	N/A
Texas	5,547	\$8,583	\$2.42
Utah	161	\$4,770	\$0.37
Vermont	71	\$4,714	\$0.57
Virginia	598	\$5,270	\$0.46
Washington	976	\$4,655	\$0.80
West Virginia	244	\$4,311	\$0.58
Wisconsin	935	\$4,713	\$0.84
Wyoming	31	\$5,326	\$0.34

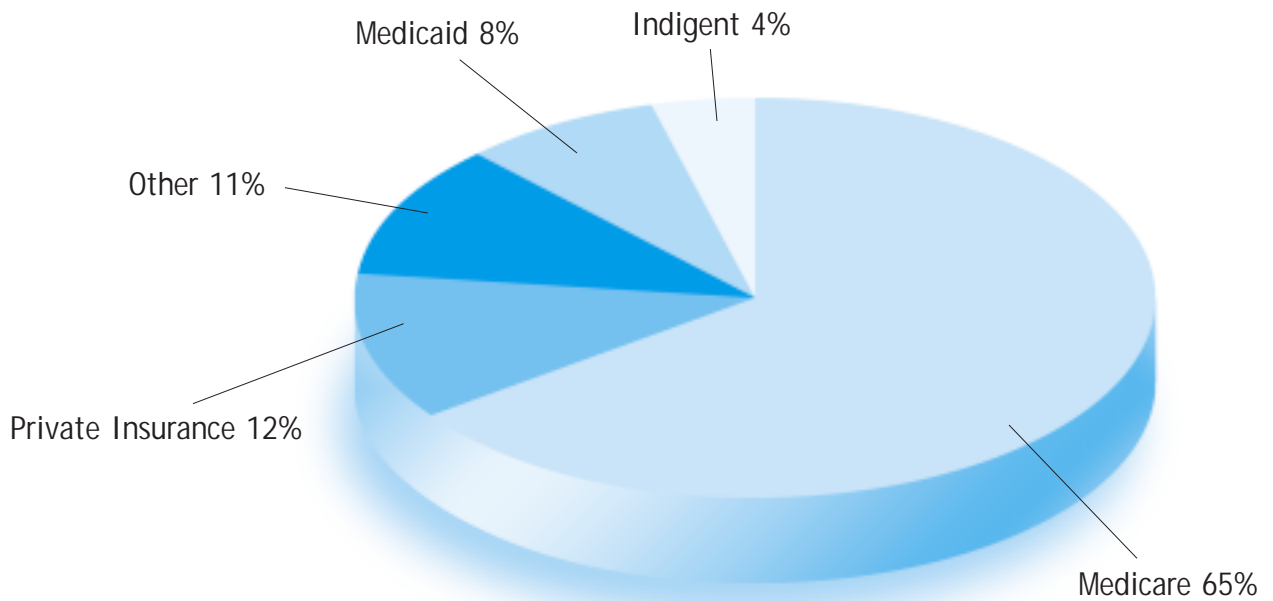
Source: Urban Institute estimates based on data from HCFA-2082 and HCFA-64 reports and July 1998 population estimates from the Population Estimates Program, Population Division, U.S. Census Bureau.

Chart 1. Selected Features of the Case Study Sites

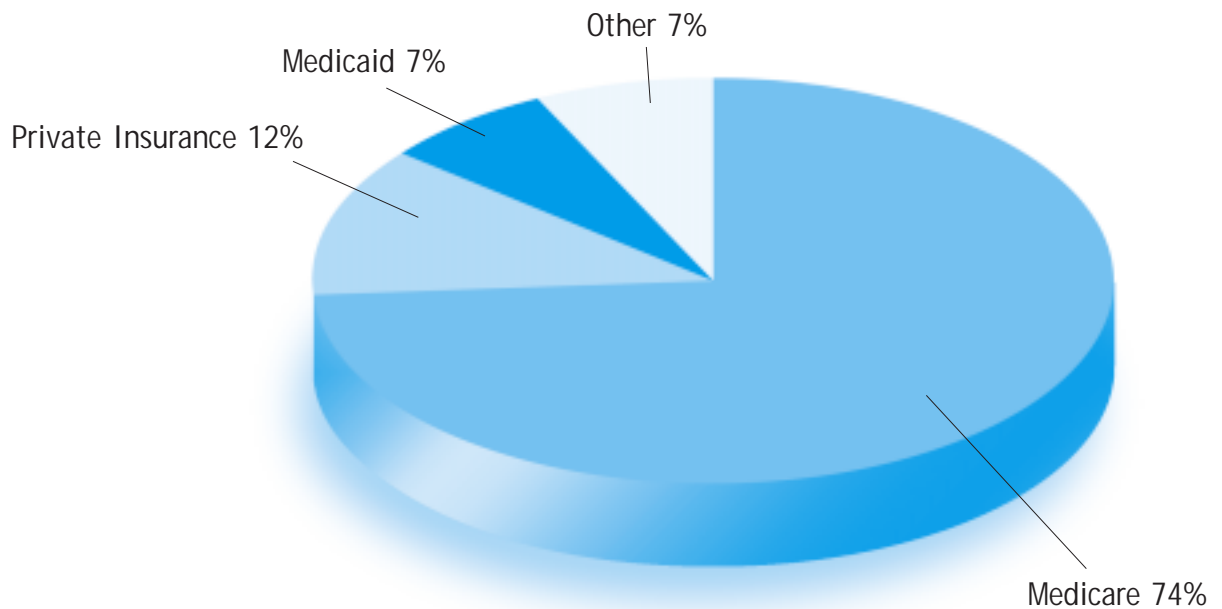
	Community Medical Alliance	On Lok	EverCare	Florida Hospice of the SunCoast
Plan Sponsorship	Subsidiary of Neighborhood Health Plan-a non-profit managed care plan.	Non-profit managed care plan.	A for-profit Medicare managed care plan, which is a subsidiary of United HealthCare Corporation.	Non-profit hospice.
Population served	All enrollees are Medicaid beneficiaries -persons with advanced AIDS or severe disabilities; and technology dependent children, high risk children and adolescents with major behavioral health problems.	Persons age 55 and older who need nursing facility care. About 90 percent of enrollees are dually eligible for Medicare and Medicaid.	Medicare beneficiaries who are eligible for parts A and B and who live in nursing homes. 70 percent are dually eligible for Medicare and Medicaid.	The hospice serves three categories of Medicaid beneficiaries - dying children and adults, patients with AIDS, and nursing home residents who are dually-eligible.
Enrollment	Voluntary.	Voluntary.	Voluntary.	Voluntary.
Composition of team managing care	Physicians and nurse practitioners.	Physicians, nurse practitioners, social workers, therapists, dietitians, and transportation and home care workers.	Physicians and nurse practitioners.	Physicians and nurse practitioners.
Capitated Payments	Annual negotiation of rates with the Massachusetts Medicaid based on costs incurred during the previous fiscal year.	Medicare's payment is 2.39 times the adjusted average per capita cost. Medicaid's payment is 90 percent of what the state pays for a nursing home resident in the San Francisco Bay area.	Medicare's payment is the adjusted average per capita cost minus five percent. Medicaid's payment is based on adjusted average per capita cost.	Hospice receives Florida Medicaid rates for physician, nurse practitioner, home care aide, and hospice services provided.
Quality Assurance Methods	Comparison of utilization data to benchmarks, such as admissions to hospital, and frequency of contacts with enrollees; incidence of decubitus ulcers, and immune system functioning in the AIDS population. Patients also have grievance procedures they can use.	Annual analysis of deaths and comfort care plans. The Interdisciplinary Teams' performances are compared and education is provided as necessary.	A clinical quality committee meets monthly to discuss quality issues and progress with the plan's quality initiatives. The plan also tracks sentinel events, such as unexpected deaths.	Annual audits of service delivery, tracking of patient and family complaints, and consumer satisfaction surveys. The quality assurance programs are tailored to the local results on these measures.

Figure 1—Distribution of Hospice Patients and Revenues by Payer Source, 1995

Distribution of Hospice Patients by Source of Coverage, 1995

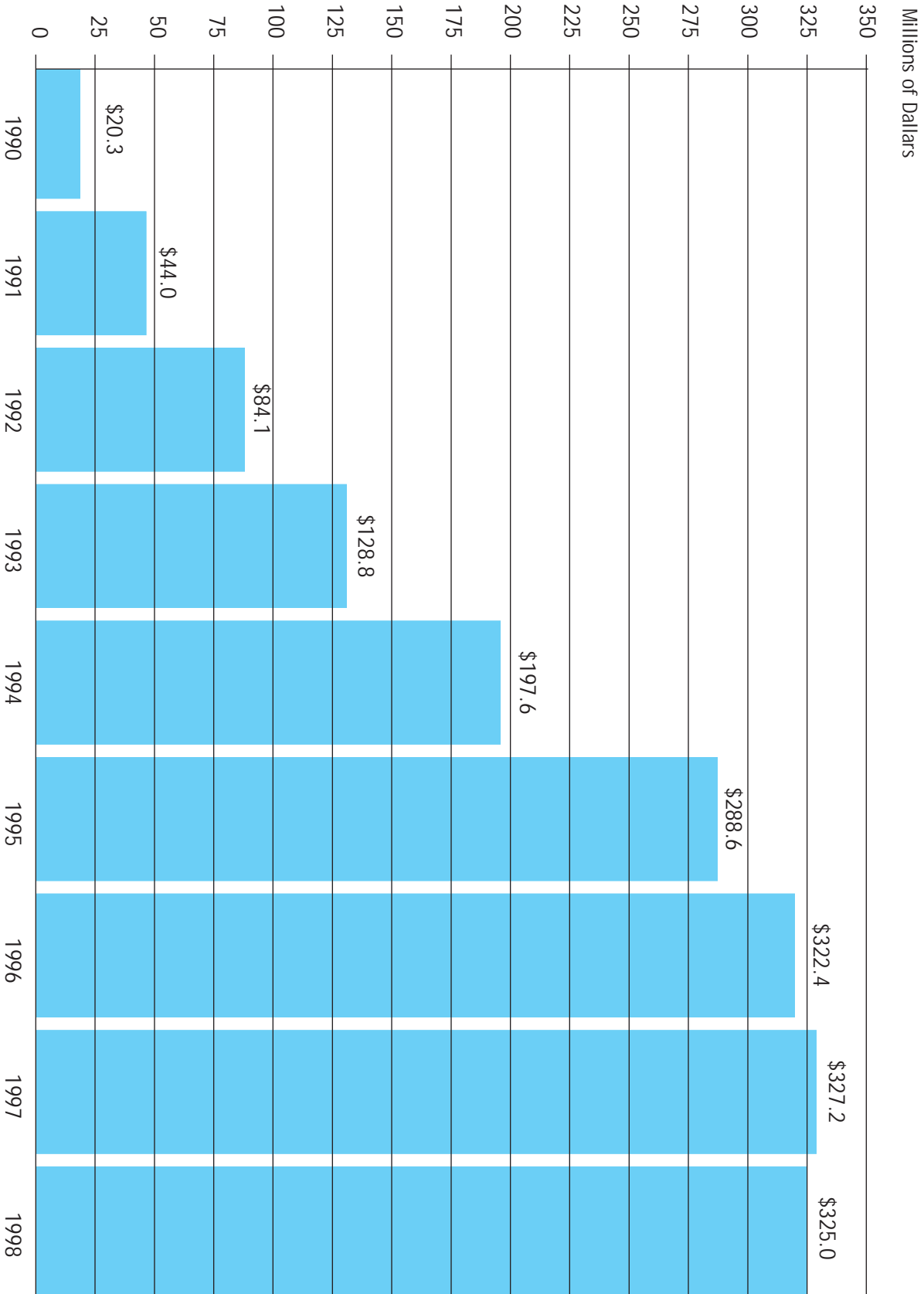


Distribution of Hospice Revenues by Payer Source, 1995



Source: *Facts and Figures on Hospice Care in America*, National Hospice and Palliative Care Organization, 2001

Figure 2—State and Federal Medicaid Hospice Expenditures, Federal Fiscal Years 1990-1998



Source: Urban Institute Estimates based on HCFA-64 data.

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