

**Hospice Association of America**  
**2005 Legislative Blueprint for Action**

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# HOSPICE ASSOCIATION OF AMERICA

## Introduction

Hospice services reinforce and supplement the care provided by family members and friends and encourage maximum independence of thought and functioning, as well as preserving human dignity. Hospice is a crucial part of humane, cost-effective care in the final stage of life. The Medicare Hospice Benefit began in 1983 primarily to serve terminally ill cancer patients. Based on this success, hospices have now greatly expanded their end-of-life care expertise to allow terminally ill Americans with other diagnoses such as amyotrophic lateral sclerosis (ALS), dementia, heart, HIV, liver, pulmonary and renal diseases; as well as stroke and coma, to receive hospice services.

The Hospice Association of America (HAA) is proactively representing its members in this new and fast-paced environment. HAA's 2005 Legislative Blueprint for Action presents a comprehensive plan for addressing major health care initiatives facing hospice providers and reflects our agenda for the 109th Congress. The Blueprint emphasizes the increasingly important role hospice plays in the continuum of health care delivery. This publication includes our members' priorities and recommendations concerning hospice care. The Blueprint was created with input from HAA's members during the year as issues developed and through a survey of the membership at the end of 2004. The issues were compiled and then reviewed by the Government Affairs Committee and approved by the Board of Directors.

This document has been produced by the Hospice Association of America, a professional association representing hospices and their thousands of caregivers who provide services to America's terminally ill patients and their families. HAA hopes this document will be helpful to Congress in its deliberations in 2005 and that it will result in the enactment of legislation to improve the quality of life for the thousands of Americans who must trust others for their help and protection.



## UPDATE MEDICARE HOSPICE BENEFIT

**ISSUE:** The Medicare Hospice Benefit (MHB) was created in 1982 to care for terminally ill cancer patients. Recent statistics from the Centers for Medicare & Medicaid Services (CMS) show that cancer patients represented only 57.4 percent of those now being cared for under the MHB. The balance consisted of conditions for which it is more difficult to determine the terminal stage, such as congestive heart failure, chronic obstructive pulmonary disease, stroke, and Alzheimer's disease. These circumstances have resulted in a growing decline in the length of stay (LoS) on the MHB. The current reimbursement structure was created by estimating the original cost of delivering routine home care (95 percent of the care given) by analyzing data collected during the 1980–1982 Medicare Hospice Demonstration Project. Although there have been significant technological, pharmaceutical, and medical delivery advances made over the past 20 years, there has been no reimbursement adjustment specific to them. The shorter LoS increases per diem costs for each patient. In 1983, 20 percent of patients received hospice services for seven days. In its June 2004 Report to the Congress, the Medicare Payment Advisory Commission (MedPC) reported that from 1998 to 2002, Medicare hospice data shows that of the patients dying in hospice, 25 percent were on the benefit for less than a week. Between 2001 and 2002, the average length of stay increased from 50 days to 55 days. However, the median length of stay remained at 16 days.

Increased costs for pharmaceuticals and pharmacotherapy for symptom control and pain management have resulted in a dramatic rise in their percentage of average daily costs from 3 percent in 1983 to 13 percent in 1999. The advancement in technology has resulted in increased outpatient services such as palliative radiation therapy and chemotherapy with accompanying diagnostic procedures required to monitor responses and side effects resulting in increased outpatient services costs from 6 percent to 15 percent of daily costs for routine home care.

The combination of decreased LoS and significantly increased costs makes it very difficult for hospices to continue providing much needed services.

**RECOMMENDATION:** Congress must take action to ensure terminally ill Medicare beneficiaries will be able to access the MHB when they reach the final stage of life. Congress should immediately:

1. Mandate a new hospice demonstration to collect data necessary to restructure the Medicare Hospice Benefit to reflect care currently given.
2. In the interim, mandate creation of:
  - a) An outlier payment policy to cover high tech treatments such as renal dialysis, mechanical ventilation, palliative radiation therapy, chemotherapy and high cost specialized drugs, and
  - b) A payment floor of the routine home care rate for 14 days to ease the burden of the short LoS.

**RATIONALE:** Congress asked MedPAC to provide a report on the adequacy of the MHB reimbursement rates by June of 2002. However, the data used for their analysis was to be from the new hospice cost reports, most of which have had postponed filing deadlines. There are flaws in the cost report which made the data questionable but, in June 2004, MedPAC recommended that CMS

evaluate hospice payments to ensure consistency with costs. The demand for hospice services will continue to increase. We must ensure this most humane service for America's terminally ill patients and their families remains a benefit to which we can turn in our hour of greatest need—the final stage of life.

## **PROVIDE SUFFICIENT HOME CARE AND HOSPICE PAYMENTS SO THAT AGENCIES CAN PROVIDE APPROPRIATE WAGES AND BENEFITS TO CLINICAL STAFF**

**ISSUE:** The severe limitations on reimbursement under Medicare and Medicaid make it extremely difficult for agencies to comply with any requirements to increase wages, much less provide wages and benefits that reflect the worth of the care provided by nurses and paraprofessionals. In fact, current economic restrictions have resulted in many agencies cutting staff or seeking ways to save on patient care costs by limiting workers' hours or reducing wages or benefits. Payment under the new prospective payment system for home health and payment rates for hospice care services must be adequate to allow for increased wages and benefits for nurses and home care aides.

**RECOMMENDATION:** Congress should provide that federal programs (Medicare/Medicaid) that finance home care and hospice services adjust reimbursement to allow for appropriate wage and benefit levels for all clinical staff. Additionally, Congress should consider implementing a wage pass through for home care and hospice workers under Medicare and Medicaid.

**RATIONALE:** Studies indicate that low wages affect an agency's ability to recruit and retain clinical staff. Agencies throughout the nation have begun to experience severe hardships in recruiting and retaining clinical staff.

Because of low wages and benefits, home care aides are often cited in Congressional testimony as an example of a work force which would benefit from an increase in the minimum wage. And, increasingly, efforts are being made to document the relationship between wages and quality of care. In 1996, the Older Women's League's report, "Faces of Care: An Analysis of Paid Caregivers and Their Impact on Quality Long Term Care," linked paraprofessional wage and benefit issues directly to quality of care issues.

Without sufficient reimbursement, financially strapped home care and hospice agencies are finding it extremely difficult to provide quality care and pay competitive wages.

## IMPROVE APPLICATION OF WAGE INDEX FOR MEDICARE HOME HEALTH AND HOSPICE

**ISSUE:** Since the inception of the Medicare per visit cost limits, home health payment rates have been adjusted to reflect varying wage levels across the nation through the application of a wage index. This payment rate adjustment continues under the Medicare home health prospective payment system (PPS), which was implemented effective October 1, 2000. However, the wage index that has been utilized by the Centers for Medicare & Medicaid Services (CMS), in accordance with Congressional mandate, has been based upon varying wages within hospitals across the nation. This index is derived from data that explicitly excludes any home health services costs. An attempt some years back to create and utilize a home care-specific wage index failed due to the unavailability of reliable wage data.

While the home health payment rates are based upon the application of a hospital wage index, the index utilized and its manner of application is significantly distinct from that utilized relative to hospital services payment rates. Of particular concern is the fact that hospitals are allowed to secure a geographic reclassification for application of the wage index by establishing that the particular hospital draws on an employment pool different from the geographical area to which it would otherwise be assigned for its wage index level. Home health agencies and hospices are not authorized to secure a wage index reclassification. As a result, a hospital may compete for the same health care employees as a hospice or home health agency but be approved for a relatively higher payment rate through the wage index reclassification. Additionally, Congress has established specific wage index criteria for certain geographic locations. However, these criteria apply only to hospitals. Finally, hospitals are provided extra protection against losses due to dramatic drops in their wage indices by a provision imposing a “rural floor” under which no hospital’s wage index can fall below the state-specific rural wage index.

**RECOMMENDATION:** Congress should allow hospices and home health agencies to obtain a geographic reclassification for wage index purposes in a manner comparable to that available to the hospitals or to allow reclassifications automatically when a hospital in the geographic locale of the hospice or home health agency receives a reclassification. Additionally, Congress should enact legislation that limits a home health agency’s loss of income due to a dramatic shift in the agency’s wage index (for example, limit the drop in any agency’s wage index from one year to the next to 2 percent).

**RATIONALE:** In today’s health care environment, health care providers of all types compete for employment of the same personnel. The adjustment of Medicare payment rates intended to reflect variations in wages across the nation should be consistent across all provider types. With increasing shortages of health care personnel, unequal wage index adjustments for health care providers in the same geographic region results in an uneven and discriminatory distribution of the employment pool of personnel. Further, in recent years some agencies have experienced dramatic increases and drops in their wage indices. This degree of “swing” in reimbursement can have a significant impact on an agency’s financial viability.

## **REQUIRE HOSPITAL DISCHARGE PLANNERS TO DISCUSS HOSPICE OPTION**

**ISSUE:** In 1994, Congress passed legislation that would require hospital discharge planners to inform appropriate patients about the availability of the Medicare Hospice Benefit. Section 146(b)(5) of the Social Security Act Amendments of 1994 (Public Law 103-432) mandated that “the hospital conditions of participation with respect to discharge planning be modified to require an evaluation of a patient’s likely need for appropriate post-hospitalization services, including hospice services and the availability of those services.”

The Centers for Medicare & Medicaid Services (CMS) has stated they are currently in the process of rewriting the hospital conditions of participation and would look at expanding the discharge planning section to reflect this legislative mandate. However, CMS has concluded that there is no legislative mandate for the hospital to supply a listing of qualified hospices available to provide hospice services.

**RECOMMENDATION:** Congress should mandate that the hospital conditions of participation require the provision of a list of available, qualified providers.

**RATIONALE:** If the hospital discharge planner conducts an evaluation of a patient’s likely need for hospice services but does not give a list of available, qualified providers, the patient and their family will then have to search out the hospices in their community. It is less likely the patient will receive needed services in a timely manner. When a patient is at this most critical time of life, every day has added intensity of meaning. Our nation’s health care system should provide appropriate information to ensure the most vulnerable in our society spend their final days in the peace, comfort and dignity they deserve.

## **OPPOSE DECREASING HOSPICE REIMBURSEMENT FOR DUALY ELIGIBLE PATIENTS RESIDING IN NURSING FACILITIES**

**ISSUE:** Since 1989, terminally ill Medicare patients living in nursing homes could elect the Medicare hospice benefit (P.L. 101-239). When a patient is entitled to both Medicare and Medicaid, the state Medicaid program must pay the hospice at least 95 percent of the nursing home rate for room and board services as set forth by each state's Medicaid program. The hospice then reimburses the nursing home.

The contractual relationship between hospice programs and nursing homes has been under the scrutiny of the Department of Health and Human Services Office of Inspector General (OIG). In its report, *Hospice Patients in Nursing Homes*, OIG made recommendations to eliminate or reduce the Medicare or Medicaid payments for hospice patients living in nursing homes. If this action is taken without further data gathering and analysis of the nature and cost of hospice care provided in the nursing home, it could result in the complete lack of, or diminished access to, appropriate hospice services for these individuals.

**RECOMMENDATION:** Congress should oppose any legislation that would decrease the reimbursement for hospice services for dually eligible patients residing in nursing facilities without appropriate data collection and analysis supporting such a change.

**RATIONALE:** Legislative changes to the hospice reimbursement and nursing home room and board reimbursement prior to an in-depth study and analysis of the services provided and the cost of those services will, in effect, deny access to a humane and compassionate approach to care for bona fide eligible terminally ill residents of nursing homes. Only after appropriate data collection and analysis is performed should any adjustments to Medicare or Medicaid payments be made.

## **ASSURE SNF/NF MEDICARE BENEFICIARY RESIDENT'S RIGHT TO CHOOSE A HOSPICE PROVIDER**

**ISSUE:** In 1989, Public Law 101-239 mandated the ability of terminally ill Medicare beneficiaries residing in skilled nursing facilities/nursing facilities (SNF/NFs) to access services under the Medicare Hospice Benefit (MHB). As SNF/NF residents become aware of the MHB, more of them are seeking hospice services. However, the SNF/NF has the right to deny hospice services to their residents or at a minimum choose the hospice the SNF/NF will allow to provide the services.

Currently, a terminally ill SNF/NF resident may only access the Medicare Hospice Benefit if the SNF/NF will allow this to occur. If the facility agrees to permit a hospice to provide services for the SNF/NF resident, the Hospice and SNF/NF must have a written agreement which specifies the coordinated services each provider will perform.

**RECOMMENDATION:** Congress should mandate that eligible Medicare beneficiaries residing in SNF/NFs have the right to receive hospice services from a Medicare-certified hospice of their choice.

**RATIONALE:** Medicare beneficiaries eligible for the Hospice benefit should have the right to choose which hospice will serve them. In March, 2000, the Office of Disability, Aging and Long-Term Care Policy, Department of Health and Human Services, and the Urban Institute released a study, "Outcomes and Utilization for Hospice and Non-Hospice Nursing Facility Decedents." This study resulted in six reports: 1) Synthesis and Analysis of Medicare's Hospice Benefit: Executive Summary and Recommendations; 2) Important Questions for Hospice in the Next Century; 3) Medicare's Hospice Benefit: Use and Expenditures; 4) Use of Medicare's Hospice Benefit by Nursing Facility Residents; 5) Outcome and Utilization for Hospice and Non-Hospice Nursing Facility Decedents; 6) Hospice Benefits and Utilization in the Large Employer Market.

The study showed that:

- Hospice patients in daily pain are twice as likely to receive level 3 analgesics as are non-hospice patients in daily pain.
- Hospice patients are less likely to be restrained, to receive tube or parenteral/IV feedings and to be given medications via intramuscular or intravenous routes.
- Hospice patients receive less occupational, speech and physical therapy.
- Hospice patients consistently have fewer hospitalizations, with the greatest differences observed 30 days prior to death (9.8 percent vs. 31.7 percent).
- A nursing facility's hospice concentration appears to have a strong influence on the hospitalization patterns of non-hospice patients. Non-hospice patients in a nursing facility with no hospice involvement had a 30 percent probability of dying in a hospital. Where there was a .01 to 5 percent hospice concentration, non-hospice patients had a 24 percent probability of dying in a hospital. Patients of nursing facilities with a 5+ percent hospice concentration had a 21 percent probability of dying in a hospital.

## **PROTECT HOSPICE AGENCIES FROM THE IMPACT OF SEQUENTIAL BILLING**

**ISSUE:** The Centers for Medicare & Medicaid Services (CMS) has imposed the longstanding hospital sequential billing policy on hospice agency claims. The policy prohibits providers from submitting claims for care to beneficiaries where previously submitted claims are pending. Claims processing can be delayed for weeks or months for many reasons, including medical review activities, common working file problems, CMS or fiscal intermediary (FI) claims processing problems, and pending claims from other providers. Hospices have continued to serve patients even though Medicare payments have been delayed for months.

**RECOMMENDATION:** Congress should require CMS to process and pay all clean claims as submitted regardless of whether previous claims have been processed, and pay interest on claims that are not processed in a timely fashion.

**RATIONALE:** Hospices are small businesses with little financial reserve, dependent on uninterrupted payment for services delivered. Interruption of payment for weeks or months, while requiring agencies to continue services to hospice patients, can result in severe financial hardships.

## **REQUIRE COVERAGE OF HOME CARE, HOSPICE AND PERSONALCARE SERVICES IN ANY MEDICAID REFORM**

**ISSUE:** Title XIX of the Social Security Act (Medicaid) requires that, in order to receive federal matching funds, certain basic services must be offered in any state's program. These are:

- inpatient and outpatient hospital services;
- prenatal care;
- physician services;
- skilled nursing facility services for individuals age 21 and older;
- home health care for persons eligible for nursing facility care;
- family planning services and supplies;
- rural health clinic services;
- laboratory and x-ray services;
- pediatric and family nurse practitioners services;
- certain ambulatory and health center services;
- nurse midwife services; and
- early and periodic screening, diagnosis, and treatment (EPSDT) services for children.

Home health services covered by Medicaid include three mandatory services: part-time nursing, home health aide, and medical supplies and equipment; and one optional service category: physical therapy, occupational therapy, or speech pathology and audiology services.

States may also receive federal funding for 32 optional services, including personal care services and hospice care.

**RECOMMENDATION:** Congress should require mandatory coverage of home care, hospice, and personal care services and home care medical supplies to all populations receiving Medicaid coverage.

**RATIONALE:** Home care and hospice services are basic to any individual's well-being and are critical to the health of this nation's poor. Home health is already greatly underutilized even as part of the basic Medicaid benefit package. This problem is only exacerbated as more managed care entities provide Medicaid services. Historically, managed care plans provide less home care services than traditional Medicaid.

Home care and hospice services are cost-effective and should be available to all those in need. The Medicaid program could realize substantial cost savings by caring for people in their homes.

## **ENSURE ACCESS TO MEDICATIONS NECESSARY FOR PAIN CONTROL**

**ISSUE:** Inadequate pain management has been identified by experts in the field as a national health concern. Recently proposed legislation, which states that controlled substances may be used legitimately for treating pain, may inadvertently compromise the quality of palliative care because it empowers drug enforcement officials to prosecute physicians to determine their intent for prescribing medication. This could have the unintended consequence of discouraging or limiting physicians from adequately treating terminally ill patients. This type of legislation would create a negative impact on the basic needs and rights of terminally ill patients as well as their comfort, dignity and freedom from pain.

**RECOMMENDATION:** Congress should oppose any legislation that would directly or indirectly set limits or prohibit physicians from prescribing adequate and appropriate controlled substances for the management of pain related to terminal illness.

**RATIONALE:** Terminally ill patients should not suffer due to inadequate pain management and lack of access to appropriate medications. Creating laws and policies that impose arbitrary limitations on physicians who prescribe controlled substances could have the unintended consequences of discouraging or limiting them from adequately treating terminally ill patients.

## **INCLUDE IN-HOME RESPITE CARE IN THE MEDICARE HOSPICE BENEFIT**

**ISSUE:** In 1982, when Congress enacted the Medicare hospice benefit, the issue of providing family support during the death and dying of their loved ones was apparent. Nowhere was this more evident than in the legislative provision that allowed for respite care so that families did not “burn out” and become unable to provide informal care to the family member who was dying. As originally intended, respite care was to include both in-home respite and inpatient respite services. However, when the four daily payment rates were established, respite care was identified as being inpatient respite care only. In-home respite care, which makes the most sense as far as home-based hospice care is concerned, is not available or financially feasible for the hospice provider.

A demonstrated need exists for reimbursement of non-skilled respite services in the home. Without this important service, patients who require around-the-clock non-skilled assistance, who may be receiving part of these services from family caregivers and who desire to remain at home, will have to be institutionalized.

**RECOMMENDATION:** Congress should establish a separate payment category in the Medicare hospice benefit for in-home respite care.

**RATIONALE:** The Medicare hospice benefit as currently constructed permits inpatient respite care services to be provided in a skilled nursing facility or an intermediate care facility and for 24-hour acute/crisis skilled nursing services in the home. There is nothing in between. Patients who have need of a home care aide on a continuous basis of 8 to 16 hours are unable to obtain that service without considerable out-of-pocket expense.

When some relief is available from the hospice, it rarely is available for the evening or night hours, when caregiver families are most likely to need respite support to prevent “burn out.” Provision of an in-home respite care category would allow many patients to remain in their homes, particularly those terminally ill patients who live alone and/or who have other problems that require support for longer than a routine visit but less than 8 hours of skilled nursing services. It is not only reasonable but humane to permit the patient to die at home with adequate support if this is desired by the patient and the family.

## **REQUIRE MEDICAL RESIDENTS AND INTERNS TO HAVE HOME CARE AND HOSPICE EXPERIENCE AS PART OF THEIR GRADUATE MEDICAL EDUCATION**

**ISSUE:** Medicare pays for the education of medical residents and interns at virtually all hospitals in the United States. Much of the education is biased toward care provided in the hospital setting. However, a great deal of medical care is moving out of hospitals into the community. Several factors precipitated this shift. Advances in medical technology allow for treatments such as infusion therapy to be provided in the home setting. Existing financial incentives for hospitals to discharge patients quickly means that services such as rehabilitation are now being provided in the home rather than the acute care setting and special arrangements for intensive home therapy prior to hospitalization in the case of chemotherapy, for example, are increasingly commonplace.

In addition, the marked increase in lifespan has resulted in an increasingly elderly population with chronic illnesses which, while they limit functioning, are not life-threatening, and therefore are managed in non-acute settings, primarily the home. Medicare requires physicians to sign for home care, but many physicians may have never practiced outside of a hospital. Often, doctors discharge patients to their home without considering the home environment, support system, and resources.

Physicians must learn to function effectively in “non-traditional” care sites, particularly the home setting. As few medical schools provide their students with comprehensive home care experiences, such education must take place at the residency level. A 1994 survey of US medical schools showed that only half of all medical schools afford the opportunity for home health and hospice education before graduation.

**RECOMMENDATION:** Congress should mandate that all residents and interns have home care and hospice experience included in their curriculum.

**RATIONALE:** Medicare pays for the direct costs of graduate medical education. The mandate that residents and interns spend time in the community does not add costs. Currently, Medicare will reimburse a hospital for residents’ time spent in education outside of the hospital as long as the resident spends his or her time in patient care activities.

In the community, residents will learn about the services available and will be better able to coordinate care between the hospital and the home setting. The importance of this increases as hospitals continue efforts to shorten lengths of stay. Indeed, it is now essential to prevent unnecessary hospitalization and long-term institutional care. Moreover, increased understanding of home health services will aid physicians in later determining appropriate levels of Medicare home health utilization for individual beneficiaries. At a minimum, education should include pain and symptom control and a requirement to make home visits.

## **ENSURE ADEQUATE HOME CARE AND HOSPICE PERSONNEL, PARTICULARLY IN RURAL AND OTHER UNDERSERVED AREAS**

**ISSUE:** There is an increasing need for home care and hospice services as a result of the aging of the population, clarification of Medicare coverage policies, continued earlier hospital discharges, and patient preferences for home care and hospice. During the mid-1990s, home care visits and hospice services under the Medicare program increased substantially. While this trend has leveled off, home care and hospice providers continue to report shortages of nurses, home care aides, therapists and social workers, especially in rural areas. The cuts in Medicare home health reimbursements have made it increasingly difficult for agencies to offer competitive wages and benefits. Increased regulatory burdens on home visiting staff have also discouraged workers from continuing in home care.

Home health agencies generally require that newly-hired staff have one year of prior work experience because they cannot afford to provide the level of supervision new nurses and therapists need in the home setting. Reductions in the workforce in inpatient settings have greatly reduced the opportunities for nursing and physical and occupational therapy graduates to obtain on-the-job experience.

Recruitment and retention of home care and hospice personnel, including nurses and home care aides, is especially difficult in rural and other underserved areas. Providing health care in these areas requires special knowledge, education, and commitment on behalf of health care providers. Continuing education and training often are not readily available. Health care services can be particularly interdependent in rural communities: when a rural hospital closes, many affiliated health care personnel and services leave the area as well.

In 2004, the Office of Occupational Statistics and Employment Projections at the Bureau of Labor Statistics, within the U.S. Department of Labor, released new employment projections for the American workforce from 2002–2012. Health services sectors are projected to grow substantially during this 10-year period. In fact, 12 of the 30 fastest growing occupations are related to health care. The projected job growth in the health care occupational sector includes increases in the following occupations: home health aides, an increase of 48 percent; physical therapist aides, an increase of 46 percent; physical therapist assistants, an increase of 45 percent; occupational therapist aides, an increase of 43 percent; personal and home care aides, an increase of 40 percent; occupational therapist assistants, and increase of 39 percent; and physical therapists, occupational therapists, and respiratory therapists, each with an increase of 35 percent.

It is critically important to both increase the supply of qualified health care staff to maintain patient care access and to assure that these staff have the skills needed to provide high quality treatment and rehabilitation services in the home setting. Federal and state regulations should promote the use of nurse practitioners, physician assistants, and other qualified home health personnel.

Congress took legislative action in the 107th Congress to help alleviate the nurse shortage. Specifically, the Nurse Reinvestment Act (H.R. 3487, P.L. 107-205) would establish a National Nurse Service Corps to provide scholarships and loans to nursing students who agree to serve in a public or private non-profit health facility, including home care agencies and hospices, determined to have a critical shortage of nurses. The legislation also establishes nurse retention and patient safety

enhancement grants to assist health care facilities to retain nurses and improve patient care delivery by encouraging more collaboration between nurses and other health care professionals and more involvement by nurses in the decision-making process.

In addition, the bill establishes grants for comprehensive geriatric nurse training, establishes a faculty loan cancellation program, establishes a career ladder program that will assist individuals in the nursing workforce to obtain more education, and establishes partnerships between health care providers like home care agencies and schools of nursing for advanced training. Lastly, the bill establishes a fund for public service announcements that will advertise and promote the nursing profession and educate the public about the rewards of nursing.

**RECOMMENDATIONS:** Congress should fund grant programs for educating therapists, medical social workers, nurses, home care aides, and other home care and hospice personnel with a focus on home- and community-based practice in areas where shortages exist. The number of schools providing therapy programs must be increased and the number of slots available in these schools should be expanded. Special incentives such as loan-forgiveness programs to fund schooling and education should be developed to recruit students for practice in geographic areas with staff shortages, such as rural and inner city areas. Grants to educational facilities should be made available for innovative approaches to recruitment and education of home health care personnel, including consideration of job “ladders” and “classrooms without walls.”

Congress should fund home care internship demonstration projects for nurses and physical and occupational therapists to provide a year of on-the-job education for new graduates.

Congress should request GAO and Medicare Payment Advisory Commission (MedPAC) studies on the shortage of personnel in home care and hospice settings, with special attention to rural and inner-city areas, and with recommendations on what can be done to overcome this problem.

**RATIONALE:** The demand for home care and hospice services will continue to increase as the elderly and disabled population grows. More qualified personnel are necessary to meet the increased needs. These personnel should have skills that enable them to apply their services to home- and community-based care situations. Further, these qualified home care and hospice personnel should be encouraged to practice in rural and underserved areas. When professionals are scarce, costs for providing care increase. Putting funds into education and other incentive programs will ultimately lower costs to consumers.

## **REQUIRE DEMONSTRATION PROJECTS TO STUDY SPECIAL SERVICES AND FINANCING OF END-OF-LIFE CARE**

**ISSUE:** People in the last phase of life need a different care system for many months or sometimes years before death. Eligibility for the Medicare hospice benefit is limited to people who have a terminal illness with a prognosis of six months or less. Most people die slowly of relentless but rather unpredictable chronic illness and disease. Studies show that almost 80 percent of Americans die in institutions where they often receive futile high-tech interventions and are in pain. Currently, the last year of life Medicare beneficiary spending is almost six times more than for those who are not in their final year of life. The last month expands to 20 times as high as average monthly expenditures for those not in their last year of life due to rapid acceleration of inpatient hospital spending. About 28 percent of Medicare funds are now spent on care in the last phase of life, which is comprised, for the most part, of expensive, high-technological interventions and “rescue care.”

Children in the last phase of life need a different care system for many months or sometimes years before death. With children having potentially life-threatening conditions, it is particularly hard to predict how many months or years a child has remaining. Often parents are reluctant to stop aggressive treatment until the very end.

Demonstration projects are needed to study special care needs and financial reimbursement for comprehensive services for end-of-life care for children and for Medicare beneficiaries who are seriously ill or who suffer from a medical condition that is likely to be fatal

**RECOMMENDATION:** Congress should enact legislation that would provide for demonstration projects to study special services and financing of end-of-life care in home care and hospice settings. These demonstrations should examine the needs of children as well as adults.

**RATIONALE:** Demonstration projects that study special care needs and evaluate the practices and procedures that will improve patient outcomes and resource utilization for end-of-life care would contribute valuable information about care needs and costs at the end of life.

## **OPPOSE IMPLEMENTATION OF PENALTIES FOR ERRONEOUS CERTIFICATION OF TERMINAL ILLNESS**

**ISSUE:** Medicare regulation (42CFR §418.22) requires that, in order to be eligible to elect hospice services, an individual's physician and the hospice medical director must certify, in writing, that the individual's prognosis is for a life expectancy of six months or less if the terminal illness runs its normal course. According to Medicare survival data, only 17.3 percent of patients receiving Medicare hospice survive longer than six months and half of Medicare hospice patients receive care for 16 days or less. It is often difficult to make the determination that a patient is terminally ill, because the course of terminal illness is different for each patient. A recently-published study reported that the recommended clinical prediction criteria are not effective in a population with a survival prognosis of six months or less. This information demonstrates what has been well known by those in the hospice community: that the science of prognostication is in its infancy. In a letter to all Medicare-certified hospices in the country, the then-CMS Administrator reiterated that "In no way are hospice beneficiaries restricted to six months of coverage."

**RECOMMENDATION:** Congress should oppose imposition of civil monetary penalties upon physicians for false certification of eligibility for hospice care.

**RATIONALE:** Physicians should not be punished for possible underestimation of a terminally ill patient's life expectancy. The only ones to be punished will be those patients in need of hospice services whose physicians will avoid recommending this compassionate, humane, and patient-family-centered care due to fear of penalties for erroneously underestimating their prognosis.

## **MANDATE HOSPICE COVERAGE UNDER MEDICAID**

**ISSUE:** In 1986, when Congress enacted legislation making the Medicare hospice benefit permanent, hospice care was made an option under Medicaid. Hospice care allows terminally ill patients to move out of acute care facilities into less expensive care arrangements, primarily their own homes. There, the hospice team of health care professionals and other specialists provide physical, emotional and spiritual care to make the remainder of a patient's life as comfortable and meaningful as possible. Currently, 46 states have chosen to offer the hospice benefit to Medicaid beneficiaries.

**RECOMMENDATION:** Congress should mandate Medicaid hospice coverage.

**RATIONALE:** States are gradually enacting hospice coverage under Medicaid in an effort to provide a more cost-effective and compassionate manner of caring for terminally-ill adults and children, including indigent and disabled individuals and increasing numbers of AIDS patients. Mandating hospice under Medicaid would speed access to hospice services. Hospice, with its combination of inpatient and outpatient care and case management by the interdisciplinary team composed of doctors, nurses, social workers and counselors, can provide comprehensive care for the terminally ill patient while saving taxpayer funds. But with the current decline in Medicaid dollars, some states are considering dropping their Medicaid hospice benefit.

## **ELIMINATE MEDICARE PROVISION REQUIRING HOSPICE SOCIAL WORKER TO PRACTICE UNDER THE DIRECTION OF A PHYSICIAN**

**ISSUE:** Under § 1861 (dd) (1) (c) of the Social Security Act, social workers are the only members of the hospice interdisciplinary group required to be under the direction of a physician. Social workers, as members of the interdisciplinary team, work in concert with the members of the team, which is guided by the team coordinator or clinical director. The interdisciplinary team, as defined by the hospice statute, consists of at least a doctor of medicine or osteopathy, a registered nurse, a social worker, and a pastoral or other counselor. The statute also defines the role of the registered nurse as the coordinator of the plan of care for the patient and family.

**RECOMMENDATION:** Congress should amend Section 1861 (dd) (1) (c) of the Social Security Act to eliminate the requirement that a hospice social worker function under the direction of a physician and require instead that the interdisciplinary team be under the direction of the team coordinator or clinical director and that each discipline should be under the direction of the supervisor of that discipline.

**RATIONALE:** Placing social workers under the direction of a physician imposes an unnecessary burden on the team and agency and creates needless complexity by requiring convoluted reporting patterns and organizational charts. It also undermines the concept of the team by mandating that one team member report to another team member rather than to the team leader. Social workers should report to their discipline's supervisor or the team leader, not a physician. Further, all members of the team should be under the direction of the clinical director who is responsible for the delivery of quality services in an appropriate and timely fashion.

## ENSURE THE PORTABILITY OF ADVANCE DIRECTIVES

**ISSUE:** Between 20 and 25 percent of Americans above the age of 18 have advance directives but are not assured that this legal document will be honored in any state other than the state in which it was executed. The law honoring advance directives from another state is unclear. An individual is burdened with the responsibility of having the advance directive meet the laws of any state in which he may be spending some time. There should be a nationwide policy on advance directives for individuals receiving items and services under titles XVIII and XIX of the Social Security Act (42 U.S.C. 1395 et seq., 1396 et seq.), assuring that an advance directive validly executed outside of the state in which such advance directive is presented by an adult to a provider of services be given the same effect by that provider as an advance directive executed under the law of the state in which it is presented. This would assure that an individual's decisions directing end-of-life care will be followed.

**RECOMMENDATION:** Congress should support legislation that ensures the portability of an individual's advance directive between health care facilities as well as between states.

**RATIONALE:** An advance directive belongs to the individual and should not be interfered with or interrupted by the laws of any particular state or health care facility. As an individual travels or relocates to a different state, his stated end-of-life-care choices should be honored based on the choices of the individual, not based on the location of the individual. Establishing a nationwide policy on advance directives that assures the portability of an individual's end-of-life care choices strengthens patient self-determination efforts and could encourage more individuals to communicate with families, physicians and health care providers about their end-of-life-care choices.

## **OPPOSE PROPOSALS TO “BUNDLE” HOME HEALTH AND HOSPICE BENEFIT PAYMENTS WITH PAYMENTS TO OTHER PROVIDERS**

**ISSUE:** The idea of bundling post-acute care services into hospitals’ diagnosis-related groups (DRG) payments or into other combined payments has been advanced by some Members of Congress and the Prospective Payment Assessment Commission (the precursor to the Medicare Payment Advisory Commission). In recent years, the House and Senate Budget Committees have suggested bundling to authorizing committees as an option to achieve Medicare savings.

**RECOMMENDATION:** Congress should reject proposals to bundle home health payments into hospital DRGs or other provider payments because it would cause major disruption to the health care industry, be anti-competitive, increase the federal regulatory burden and erect a new and unnecessary barrier to beneficiaries’ access to quality care.

**RATIONALE:** The proposal would make hospitals or other providers responsible for arranging and financing post-acute home health and would combine home health payments into payments to other providers. This direction is inconsistent with the prospective payment system recently implemented for home health care.

Bundling home care payments into hospital DRGs would severely compromise both the quality and availability of home health care for Medicare beneficiaries. Many hospitals have limited experience with the provision of non-hospital, post-acute care. Only 30 percent of all home care agencies are currently affiliated with hospitals. Requiring hospitals to be responsible for determining post-hospital patient care needs, quality of care, and the appropriateness of care is beyond the scope of many hospitals.

Basing post-hospital payments on DRGs is also completely inappropriate. DRGs are not designed to predict the need for or cost of home health care after a hospitalization. The post-acute care needs of a patient can be completely different from the reason for hospital admission. Home health payments based on DRG rates would not match patient needs.

In addition, the trend away from inpatient hospital care and toward promoting increased use of home care as a means of reducing length of stay means that more high-tech care and more heavy care will be provided in the home setting, making DRGs even less appropriate. In fact, many patients are now able to receive care and treatment at home from the onset of their illness, thus avoiding hospitalization altogether.

Bundling would vastly increase the administrative burden on home care providers by requiring multiple payment systems for home health—one for post-acute patients and one for patients entering home care from the community—and would require home care agencies to bill any number of hospitals for the care they provide to post-hospital patients, rather than using the current single-billing system. This two-track system will result in uneven Medicare coverage for patients with the same care needs as every hospital interprets and applies coverage rules differently. Many of these same arguments apply to proposals to bundle home health payments in with payments to other post-acute care providers.

## CLARIFY THE DEFINITION OF SEPARATE ENTITY

**ISSUE:** In recent years, home health/hospice organizations have become more complex, multi-functional entities. The appearance of these complex organizations has made it increasingly difficult for surveyors to determine what part of the organization is the certified home health agency or hospice and subject to the Medicare conditions of participation (CoP). As the result, other portions of the organization are being subject to the CoP. Many of the instructions issued in the past are outdated and provide conflicting guidelines. The current CMS guidelines provide inadequate clarity to assure consistent application.

**RECOMMENDATION:** Congress should clarify that the definitions of “home health agency” and “hospice” allow for limitation of the application of the Medicare regulations to that distinct part of the organization that is the home health agency or hospice.

**RATIONALE:** Federal law defines a home health agency as a “public or private organization or a subdivision of such an agency or organization.” Hospice is defined as a “public agency or private organization or subdivision of either of these that is primarily engaged in providing care to terminally ill individuals.” “Subdivision” is defined in the State Operations Manual as a “component of a multi-function health agency.” There is no requirement that a “subdivision” be a separate legal entity from other parts of an organization. In order to comply with federal law and the definition of “subdivision” in the State Operations Manual, an organization simply must be able to delineate the home health agency from other “components of a multi-function health agency.” This requirement is met when a home health agency or hospice has distinct admission and care management processes and a program description that differentiates the agency or hospice from other organizational programs.

## **ENSURE APPROPRIATE MEDICAID RATES FOR HOME CARE AND HOSPICE**

**ISSUE:** Medicaid has taken on an increasing role in providing coverage of home care and hospice services to children, the disabled, and the elderly. Early data indicates that Medicaid expenditures for home care and hospice services now exceed Medicare expenditures. A significant part of the reason behind the Medicaid growth is the flexibility allowed states in the structuring of Medicaid coverage and the recognition that home care is a viable, cost-effective alternative to institutional care. However, as Medicaid expenditures for home care and hospice have increased along with general strains on state Medicaid budgets, reimbursement rates have failed to keep pace with increasing costs of care and, in some cases, they have been subject to reduction for purely budgetary savings purposes. Forty-seven states have reported Medicaid-related budget problems.

Federal Medicaid law establishes a broad and somewhat ambiguous standard for rate setting that merely requires the states to set rates at a level sufficient to enlist enough providers so that care and services are available at least to the extent that such care and services are available to the general population in the geographic area. The "sufficient access" standard for rate setting operates in a manner that requires a demonstration that individuals in need of care cannot find it solely because of inadequate rates. This method fails to prevent the loss of services and only reacts when the inaccessibility to services reaches a high enough level to gain political attention.

Inadequate reimbursement for home care and hospice services has affected all populations served in the home and in all of the various home care programs available under Medicaid. Technology intensive home care services, personal care services, private duty nursing services, and basic home health services are often reimbursed at levels of payment equal to 60 to 75 percent of the cost of the provision of care. The result is a very fragile Medicaid home care benefit structure that relies on payment subsidization by non-Medicaid sources, thereby jeopardizing continued access to care.

**RECOMMENDATION:** Congress should enact legislation that requires that states continually assess Medicaid home care and hospice rates of payment and the methodology utilized for establishing rates. The legislation should further require that rates be reasonable and adequate so as to:

- Assure access to care comparable to the non-Medicaid patient population;
- Ensure reimbursement sufficient for providers to conform with quality and safety standards; and
- Guarantee payments sufficiently adequate to incentivize providers of care to operate efficiently while meeting the cost of care provision.

**RATIONALE:** Virtually all Medicaid home care reimbursement systems pay insufficient attention to the effect of payment rates on patients' access to care or the cost of efficiently delivering services. Inadequate rates also severely impact the ability of the provider to meet quality and safety standards. Requiring states to engage in an annual analysis of the rate setting methodology and the adequacy of payment rates combined with federally mandated goals for a rate setting process will ensure that Medicaid recipients receive high quality care.

## ESTABLISH MEANINGFUL STANDARDS FOR LONG-TERM CARE INSURANCE

**ISSUE:** Very few individuals can afford to pay the full cost of long-term care at home or in a nursing home out of their own pockets, yet neither Medicare nor private insurance cover those services to any great degree.

As public policy makers grapple with a better way to finance the nation's long-term care bill, the private long-term care insurance market has begun to offer an increasing number of Americans a solution. According to the American Health Insurance Plans (AHIP) latest survey, about 9.16 million long-term care insurance policies had been sold by 2002. About 18 percent were sold through employer-sponsored group plans.

While private insurance won't meet most individuals' long-term care needs, it may be appropriate for those who can afford to pay the premiums for many years and who have assets to protect.

At the same time, inadequate state regulation of the private long-term care insurance market has led to development of ineffective policies and abusive sales practices. Additionally, high lapse rates—the rates at which policy holders drop coverage before they need long-term care—have significantly reduced the impact long-term care insurance policies could have on defraying long-term care costs.

The “Health Insurance Portability and Accountability Act of 1996” (P.L. 104-191) included tax incentives for the purchase of long-term care insurance. In order to qualify for the special tax treatment, long-term care insurance policies are required by the Act to meet the standards set out in the 1993 National Association of Insurance Commissioners (NAIC) model act. The 1993 NAIC model act was specified in the legislation despite the fact that it is not the most current version, which has stronger consumer protections such as mandatory nonforfeiture of benefits. Favorable tax treatment under the legislation was limited to plans that require that beneficiaries either need assistance with at least two activities of daily living or have cognitive impairment that requires substantial supervision in order to receive home care benefits. This has meant that some plans with the most extensive home care coverage do not qualify for favorable tax treatment.

**RECOMMENDATION:** Congress should amend the “Health Insurance Portability and Accountability Act” to require that all long-term care insurance policies meet the most up-to-date federal minimum standards. The federal minimum standards should include the most current NAIC model and should require that all long-term care policies cover a full range of home care and hospice services. Home care and hospice services should be reimbursed at levels at least equal to that of nursing home care. Favorable tax treatment should be extended to more generous plans which provide home care benefits for those who need assistance with one activity of daily living (ADL) or one instrumental activity of daily living (IADL), or when home care is otherwise deemed medically necessary by a physician. Congress should look for ways to encourage creative use of the private long-term care insurance market to strengthen the Medicaid program.

**RATIONALE:** Although private long-term care insurance will not be a total solution for financing long-term care, it can help protect some people against large out-of-pocket expenses. It gives some

individuals the opportunity to retain choices and develop a flexible, planned response to a potentially ruinous financial event that will confront many people over 65 as well as many disabled people under 65.

However, state attempts to regulate the private long-term care insurance market have had only limited success. In the absence of federal regulation, consumers are left to carefully sort through the myriad policies, riders and features to find an affordable and reliable plan. The choices are complex and the figures easily manipulated. By mandating that federal requirements for all private long-term care insurance reflect the most currently accepted minimum standards, consumers will be assured adequate protections and special federal tax treatment of long-term care insurance policies will be justified. This is the same principle which was applied in a 1990 law with respect to Medigap insurance. Regulation of the market will foster confidence among consumers that private long-term care insurance constitutes a viable option for their protection from large out-of-pocket expenses in the event that they need long-term care services.