In the Place They Call Home:
Expanding Consumer Choice
Through Home and Community-Based Services

Recommendations from the
Home and Community-Based Services Development Cabinet
American Association of Homes and Services for the Aging
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OVERVIEW

How will the nation meet the service and support needs of a growing aging population, especially in light of skyrocketing care costs, consumer preferences to age in place, the growing prevalence of chronic disease, strained government budgets and a shrinking workforce? AAHSA’s Home and Community-Based Services Development Cabinet presents three sets of recommendations that call for increasing consumer choice by making home and community-based services (HCBS) an integral part of the nation’s system of long-term services and supports.

*Develop a Universal Standard of Quality for Home and Community-Based Care.* All types of HCBS providers must work together to develop a national quality standard for home and community-based services. Quality services are best provided by a multidisciplinary team that uses case management and electronic data systems to coordinate care. Government and providers must work together to strengthen the nation’s workforce and technology infrastructures so quality long-term services and supports can be delivered in the most efficient way possible.

*Create a Finance System That Promotes Consumer Choice and Quality.* Older people who are not eligible for Medicaid have fewer long-term care choices and are at higher risk for expensive hospital stays and nursing home placement. To ensure that these individuals have full access to a range of care options, Congress should establish a National Insurance Trust for Long-Term Care that would offer universal coverage for critical long-term services and supports. The HCBS Development Cabinet recommends a more equitable reimbursement system for adult day health services, a pay-for-performance system for home health care, increased reimbursement for mental health services, and improved funding for transportation providers.

*Provide More Long-Term Service and Support Options for Americans.* All older Americans, regardless of income, deserve to have equal access to the variety of long-term service and support options, including HCBS. We must offer more HCBS options, make sure that older people know enough about these options to make informed choices, bring HCBS to senior housing, and encourage more providers to add HCBS to the list of services they provide to their own residents and older people living in the community.
Section I: INTRODUCTION

As recently as 30 years ago, older adults in the United States had only two choices when they needed long-term services and supports. They could move in with a family member who would provide their care and services. Or, they could move to a nursing home.

Times have changed, and so has the field of long-term services and supports. Skilled nursing facilities continue to provide a valuable service to older people who require an intensive level of care. But over the past three decades, these nursing homes have been joined in that effort by a variety of providers, including those offering an array of home and community-based services (HCBS) to elderly who continue to live independently. HCBS providers include home health agencies, adult day services, hospices, housing communities that offer supportive services to residents and Programs of All-Inclusive Care for the Elderly (PACE), which provide a coordinated package of care and services to frail older people living in the community.

Together with nursing homes, HCBS providers offer older Americans and their families an important benefit that has been conspicuously absent from long-term care for decades – the ability to choose the level of service they will receive, to select the agency that will provide those services, and to decide for themselves where services will be delivered. A long-term service and support system that provides this kind of choice, as our current system is beginning to do, gives older people the opportunity to maintain control and self-determination in the face of frailty and disability. It honors the well-documented preference of older consumers to receive long-term services and supports in their own homes. And, it helps to preserve financial resources by ensuring that older Americans will receive the most appropriate level of care in the most efficient way possible.

A Fragmented System

In recent years, the long-term service and support system has made great strides in its efforts to create more choices for older people and people with disabilities. Words like “choice,” “self-determination,” “consumer preferences” and “quality of life” are becoming a more natural part of
the conversation when policy makers and providers discuss long-term service and support options. Yet, providers, health experts and lawmakers have not yet been successful in translating these ideals into policy and funding decisions that affect day-to-day care delivery for the majority of elderly.

The nation is increasing its expenditures for HCBS. Yet, many barriers stand in the way of more widespread access to these services. At the most basic level, the HCBS delivery system is fragmented nationwide, simply because each state has as much power as the federal government to determine reimbursement for and implementation of long-term services and supports. As a result, home and community-based services vary widely from one state to the other and, in some cases, the ability of older people to access those services has become a matter of geography rather than of need. Within states, the lack of integration between the Medicare and Medicaid programs creates a dilemma for many older people. Often, these individuals do not have enough income to pay for home and community-based services out of their own pockets. Yet, many have too much income or too many assets to qualify for HCBS under Medicaid. Other payment sources provide only limited coverage for home and community-based services.

Adding to the frustration is the often hard-to-understand fact that Medicaid eligibility is no guarantee that an older person will receive needed home and community-based services even if they are available locally. Waiver programs that allow states to use Medicaid dollars for home and community-based skilled care often have long waiting lists and strict eligibility requirements that prevent many Medicaid beneficiaries from receiving the HCBS they need and deserve.

To complicate matters even further, Medicare and Medicaid costs are increasing at an alarming rate. HCBS providers already struggle to attain funding parity in a system that has traditionally favored institutional care as the only fully funded option. For example, two thirds (63%) of Medicaid funding in 2005 went to institutional care, even though more individuals received their long-term services and supports in the community than in institutions. Now, budget trimming efforts at both the state and federal levels have targeted HCBS providers, many of whom face the possibility of funding update freezes in 2010.
This is the wrong approach. Instead of cutting back, states should be expanding home and community-based services as way to improve efficiency in the delivery of long-term services and supports. HCBS providers enhance that efficiency by providing important assessment and case management services and by working hard to ease clients’ transitions from one care setting to another. A recent study by the National Institute on Aging found that by doubling the amount of money they spend on HCBS, states can reduce by 35 percent the risk that a childless older person will enter a nursing home.¹ This population subset is five times as likely to be placed in a nursing home as other older adults.

Even a cursory review of the demographics of an aging American population should be enough to shake us out of our traditional assumptions about long-term services and supports. Clearly, by sticking with our current course, the country runs the risk of not being prepared to meet the complex needs of the future aging population. The growth of this population cohort could have staggering implications for providers and consumers of long-term services and supports. More than 37 million Americans were 65 and older in July 2006, a figure that represented a mere 12 percent of the nation’s population. By 2050, however, the over-65 population is projected to reach 86.7 million – or 21 percent of the population. The 85 and older population – the population most likely to need long-term services and supports – is projected to increase from 4.2 million in 2000 to 8.9 million in 2030.

How will the nation meet the needs of this growing population, especially in light of skyrocketing care costs, consumer preferences to age in place, the growing prevalence of chronic diseases among aging Baby Boomers, strained government budgets and a shrinking workforce? Members of AAHSA’s Home and Community-Based Services Development Cabinet have been researching and discussing these questions since October 2007.

The HCBS Development Cabinet

The 25-member Home and Community-Based Services Development Cabinet was convened by AAHSA leaders in 2007 and charged with recommending to the AAHSA Board of Directors a plan that would promote HCBS development throughout the nation. The HCBS Development Cabinet is comprised of AAHSA members working in 25 states to offer quality services that include adult day services, home care, home health, hospice, Programs of All-Inclusive Care for the Elderly (PACE), supportive housing, transportation services, senior centers, information and referral services, wellness programs, civic engagement opportunities and senior volunteer programs. One cabinet member is the executive of an AAHSA-affiliated state association of homes and services for the aging.

At the beginning of its work, cabinet members worked together to write three key documents – a Mission Statement, a Vision Statement, and Core Principles – that guided its deliberations. These documents are presented below.

**Mission Statement**

Our mission is to promote home and community-based services (HCBS) as a vital consumer-driven, long-term service and support option and a sustainable part of the continuum of aging services.

This mission will guide AAHSA and state affiliates to help create a system that provides care in a manner that makes the “normal” human response to people in need automatic. This system will educate consumers and providers to assure that they have options and access to quality HCBS. Our mission is a call for a more effective system of care in which AAHSA members collaborate with each other and with system leaders to assure that consumers have a clear choice of care in the place that they call home.
**Vision Statement**

Our vision is that individuals and families are empowered to make decisions about their own lives, and have access to a full range of long-term service and support choices.

This vision will guide AAHSA and its membership to create a sense of urgency regarding the need to develop quality home and community-based services and become a catalyst for change. The vision of the future must include a seamless service delivery system where all AAHSA members/providers work together to provide a comprehensive, coordinated approach to increase accessibility and the use of best practices on the state and federal levels. The delivery system incorporates integrated funding; partnerships among caregivers, providers, and consumers; and an educational and advocacy framework that will help our country meet the needs of the rapidly growing population of older adults and people with disabilities who live in the community.

**Core Principles**

1. Preserve self-determination by responding to individual needs and providing adequate consumer information.
2. Promote the individual’s right to take informed risks.
3. Provide adequate and flexible funding to support a wide variety of consumer-choice options.
4. Create flexibility of options and choices for aging in place.
5. Develop a person-centered care system that has simplicity of access.
6. Build in workforce development as a key component of quality.
7. Foster the idea that home and community-based services need to be recognized as a long-term service and support option, not a replacement for skilled nursing facilities.
8. Incorporate a universal approach for standards, regardless of income and services.
9. Develop a system that incorporates caregiver support for both family and professional caregivers.
Cabinet Work Groups
In addition to taking part in four in-person meetings and 24 telephone meetings, members of the HCBS Development Cabinet also participated in four work groups that researched specific HCBS issues and formulated appropriate recommendations.

1. The **State and Federal Legislation and Regulations Work Group** concentrated on legislation and regulations that promote or are barriers to home and community-based services, as well as best practices in state government for HCBS service delivery.

2. The **Funding Work Group** examined reimbursement issues and investigated innovative state programs that have improved funding and quality.

3. The **Quality of Care Work Group** focused on workforce issues, the use of technology in aging services, and quality initiatives that improve care.

4. The **Consumer Awareness and Choice Work Group** explored how consumers obtain information about their long-term service and support choices, and the role of housing and transportation options in helping older people age in place.

Cabinet Recommendations
The HCBS Development Cabinet developed 36 recommendations that it believes can serve as a blueprint for implementing a long-term service and support system that uses home and community-based services to prevent or delay nursing home placement for individuals who choose to receive care at home. A master list of all 36 recommendations appears on pages 15-18, while more detailed discussions of each recommendation begin on page 36. The cabinet based its final recommendations on extensive research into existing HCBS programs, as well as recommendations developed by the AAHSA Housing Cabinet, and the association’s Center for Aging Services Technology and Institute for the Future of Aging Services. Cabinet recommendations are divided into the following three categories:
1. **Develop a Universal Standard of Quality for Home and Community-Based Care.** The HCBS Development Cabinet chose to place its highest priority on recommendations designed to ensure that no matter where an older consumer receives long-term services and supports – at home or in a residential care setting, in rural or urban areas, and in every corner of the nation – he or she can be assured of their quality. Providing these assurances to a growing older population will require a concerted effort to ensure that a national quality standard exists for all settings, including HCBS programs.

To ensure quality, HCBS must be coordinated by a multidisciplinary team that includes the consumer, his or her primary care physician, HCBS providers and family caregivers. Case management, electronic data systems and consumer-empowerment strategies will be essential tools for enhancing collaboration among team members and involving consumers in managing their own health and health care. Government officials and providers must work together to strengthen the aging services workforce and technology infrastructures so HCBS providers can provide quality services and meaningful care choices to older people for decades to come.

2. **Create a Finance System That Promotes Consumer Choice and Quality.** The HCBS Development Cabinet is concerned about current funding of long-term services and supports for individuals who are not eligible for Medicaid. This group has fewer service and support choices. In many instances, this lack of choice results in expensive hospital stays and nursing home placements.

The HCBS Development Cabinet recommends and endorses several strategies to ensure that older people with financial needs have full access to a range of long-term service and support options. Its primary recommendation echoes AAHSA’s Long-Term Care Financing Plan, which calls for the establishment of a National Insurance Trust for Long-Term Care that would offer universal coverage for critical long-term services and supports. The trust’s funds would be supplemented by Medicare and Medicaid, which should ensure that HCBS and other long-term care providers have the capital they need to offer needed services and to recruit, train and retain qualified staff. The cabinet recommends a more equitable
reimbursement system for adult day health services, a pay-for-performance system for home health care, increased reimbursement for mental health services, and improved funding for transportation.

3. **Provide More Long-Term Service and Support Options for Americans.** Choice cannot be a luxury that belongs only to the wealthy. Instead, all older Americans, regardless of income, deserve to have equal access to the variety of long-term service and support options. The HCBS Development Cabinet supports several legislative initiatives – including *The Empowered at Home Act of 2008, The Community Choice Act of 2007* and the “Project 2020” program – which promise to expand HCBS programs and eligibility, especially for older people at high risk for nursing home placement. The cabinet endorses efforts by the Administration on Aging to ensure that eligible older people know about all of the long-term service and support options available in their communities, and possess enough information about those options to make informed choices.

The cabinet recommends several actions that will enhance the availability of home and community-based services within senior housing. These include strategies that help consumers pay for the services they require and give housing providers the resources they need to offer meal, home health and adult day services on site. Finally, the cabinet urges AAHSA members to consider adding HCBS to the list of housing and skilled nursing services they provide to their own residents and to older people living in the surrounding community. The cabinet also supports state and federal legislation that increases, rather than limits, the supply of HCBS providers.
Recommendations of the HCBS Development Cabinet

Develop a Universal Standard of Quality for Home and Community-Based Care

- Continue to encourage the federal government to make the Medical Home, and similar programs that follow the Guided Care model, a permanent part of the Medicare system. These programs should use care coordination and technology to coordinate primary, acute and long-term care services.

- Congress should create payment mechanisms to facilitate demonstration grants for Hospital at Home models of care.

- Congress should pass legislation that encourages Medicare providers to use standardized data systems, such as the CARE tool, to increase communication and care coordination among primary care, acute care and long-term care providers and to ease transitions between different levels of care.

- The federal government should give providers incentives to use electronic medical records and web-based care plans. Such initiatives as the My Shared Care Plan would improve quality and consumers’ involvement in their care.

- Congress should amend the regulation for targeted case management to ensure that chronic care management is reimbursed and that case managers have adequate time to coordinate services for an individual transitioning to the least restrictive living situation. The regulation should also ensure that older adults and persons with disabilities who are living in the community have access to comprehensive case management.

- The Centers for Medicare and Medicaid Services (CMS) should establish a standardized quality initiative for all Cash & Counseling programs. This initiative should include standards and competencies for human resources, training and evaluation. States should contract with home health agencies to train caregivers and complete evaluations for Cash & Counseling.

- CMS should require that Special Needs Plans have eligibility requirements for enrollment, quality initiatives and a standardized benefit package.

- Congress should mitigate the challenges posed by shortages in the long-term care workforce by enacting legislation that incorporates recommendations that have been developed by the Institute for the Future of Aging Services (IFAS). In the short-term, Congress should pass the Caring for an Aging America Act of 2008 and the Home Health Services Job Training and Caregiving Act of 2008.

- The federal government should provide Real Systems Change Grants to states that gradually implement and expand nurse delegation under their respective Nurse Practice Acts. States should initiate a nurse delegation system that includes consumer protection and workforce competencies.
• Congress should pass legislation that incorporates the recommendations of the Center for Aging Services Technologies (CAST) regarding how technology can improve quality in aging services and promote more efficient utilization of the long-term care workforce.

• Federal Real Systems Change Grants should be available to help states and adult day providers work together to develop a database of information on adult day programs and participant outcomes. This information could be used to conduct operational and clinical benchmarking and quality analysis. A consumer survey could also be included in this process.

• The federal government should offer Real Systems Change Grants to states that have experienced reduced consumer access to adult day services. States should use these grants to offer technical assistance and training for adult day center directors.

Create a Finance System That Promotes Consumer Choice and Quality

• Congress should pass legislation that would incorporate the recommendation, included in AAHSA’s Long-Term Care Financing Plan, to establish a National Insurance Trust for Long-Term Care.

• The federal government should provide Medicaid Transformation Grants to help states improve their systems for financing long-term services and supports.

• All providers of home and community-based services must receive sufficient annual payment updates to assure that they have the capital to recruit, train and retain qualified staff, as well as implement best practices in care.

• The federal government should gradually expand the Medicare Home Health Pay-for-Performance Demonstration Program and give it permanent status in all 50 states after it has been determined that the monitors being used are true indicators of quality and cost-effective care. An efficient Pay-for-Performance Program for Medicaid home health services should be tested in states using federal demonstration project funds. The monitors used must emphasize qualitative and quantitative outcomes that occurred because of the home health agency’s care.

• Congress should increase Medicare reimbursement for mental health services. These services hold great potential for reducing emergency room visits and inpatient hospital stays, and improving outcomes for older adults with depression. The Medicare reimbursement for counseling should be increased to expand the supply of social workers providing counseling services.

• The federal government should use Medicaid Transformation Grants to help states with an insufficient number of adult day service providers meet the care needs of older adults and
persons with disabilities. Grantees should expand the number and scope of adult day services available by implementing acuity-based reimbursement systems for adult day services.

- Congress should pass legislation that would provide coverage under the Medicare program, using the home health prospective payment system, for adult day health programs that provide skilled services.

- The federal government needs to ensure that reimbursement for transportation under Medicaid and Older Americans Act programs sufficiently covers costs. In addition, Congress should consider legislation that provides Medicare coverage for non-emergency medical transportation. The lack of available transportation to medical appointments is a leading cause of hospitalizations for older adults, especially those living in rural areas.

**Provide More Long-Term Service and Support Options for All Americans**

- Congress should enact the *Empowered at Home Act of 2008*, which would increase eligibility for home and community-based services.

- Congress should pass the *Community Choice Act of 2007*, which would add personal care to the Medicaid State Plan.

- Caregivers need tax relief to help them with the financial burden of caregiving.

- The federal government should adopt a more reasonable standard to determine poverty, such as the Elder Economic Security Initiative. This standard should replace the Federal Poverty Level as a predictor of need.

- Congress should pass legislation that establishes a Medicaid eligibility standard for individuals who are at high risk for nursing home placement.

- Congress should pass legislation that uses an increase in the Federal Medical Assistance Percentage for Medicaid home and community-based services expenditures as a way to encourage states to institute presumptive Medicaid eligibility programs.

- Congress should introduce and pass legislation to implement the Project 2020 program, which expands Older Americans Act programs to help prevent nursing home placements.

- The Administration on Aging (AoA) should encourage states to develop an accurate database that Single Point of Entry and No Wrong Door providers can use to give consumers information about all available long-term service and support options, including the Program of All-Inclusive Care for the Elderly (PACE) and adult day services.

- The AoA should establish a national training protocol for the staff of Aging and Disability Resource Centers (ADRCs), Area Agencies on Aging (AAAs), and 2-1-1 operators. This
training should include information about the services offered by all providers of home and community-based services.

- The AoA should attempt to ensure that conflicts of interest do not arise when working with ADRCs, AAAs, 2-1-1 operators and Single Point of Entry programs so that consumers are aware of all available HCBS services and that all HCBS providers are receiving appropriate referrals.

- The federal government should promote the growth of Programs of All-Inclusive Care for the Elderly (PACE) nationally as a way to increase PACE access for frail seniors who would benefit from comprehensive, coordinated and integrated care.

- AAHSA state affiliates will advocate for state governments to apply the Supplemental Security Income (SSI) Enhanced Benefit for Assisted Living to SSI-eligible individuals who reside in senior housing.

- HUD should consider designating Personal Emergency Response Systems, nutrition supplements and incontinent briefs as eligible medical deductions for subsidized housing.

- In order to promote a constellation of service options for consumers, AAHSA and its state affiliates should encourage state governments and the federal government to promote legislation that would reduce the use of moratoriums on providers of home and community-based services.

- AAHSA should encourage and assist members who operate Section 8, Section 202 and tax credit housing, continuing care retirement communities (CCRC) and nursing homes to investigate whether operating (or contracting with) an adult day service program, home care agency, PACE or clinic would fit into the organization’s long-term strategic plan.

- AAHSA should encourage and assist CCRCs to serve older adults who reside in the community by establishing CCRC without Walls programs.
Section II: A CONSTELLATION OF SERVICES

What exactly are home and community-based services (HCBS)? The answer to that question will depend on whom you ask. The HCBS Development Cabinet defines home and community-based services as all services or management of services that enable older adults to remain at home. Federal programs add layers of detail to that definition.

In defining “home and community care,” for example, the Social Security Act includes a laundry list of home and community-based services that are furnished to a “functionally disabled elderly individual” in accordance with an individual community care plan that has been established and is periodically reviewed and revised by a qualified community care case manager. Those services include household-related assistance such as homemaker and chore services; services directed to the individual, such as home health, personal care, nursing care and adult day care; and services that support families, such as respite care and caregiver training.

The HCBS Development Cabinet adds several services to the list included in the Social Security Act. These services include transportation, hospice, wellness programs, civic engagement opportunities for older adults, and service coordination in senior centers and senior housing-with-services. In addition, the cabinet delineates five primary HCBS provider types: adult day services, home health and home care, hospice, housing with services, and the Program of All-Inclusive Care for the Elderly (PACE).

Adult Day Services

Adult day programs vary greatly from state to state. However, all adult day programs have one characteristic in common: they provide a wealth of services at a reasonable cost to individuals who would otherwise have to use facility-based care. Adult day services can provide three different models of care.² A social model provides services for individuals, including those with

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dementia, who have no other chronic conditions. A medical model helps individuals manage their chronic conditions. A third model features both social and medical services. Some adult day providers may offer disease-specific programs for individuals with brain injury, HIV, dementia, mental illness, mental retardation or developmental disabilities.

Adult day providers offer a number of skilled services, including physical therapy, occupational therapy, speech therapy, nursing and nutrition counseling. However, the availability of these services can vary from state to state. Almost all adult day programs accept individuals who use wheelchairs and those who are incontinent. Most programs provide assistance with toileting, test participants’ blood sugar, administer medications and offer case management services. About half of adult day programs provide bowel and bladder training, oxygen treatments, wound care, injections, and catheter and colostomy care. Some programs also offer tube feeding, tracheotomy care and overnight care.

The growth of adult day programs in recent years has been directly related to increases in available funding sources. Public funding for adult day services began in the early 1970s, when Congress placed the U.S. Department of Health, Education and Welfare in charge of developing demonstration projects to explore alternative forms of long-term services and supports. Since then, several legislative initiatives have added adult day services to the list of long-term service and support options supported by federal dollars, including Title XX of the Social Security Act of 1974, The Older Americans Act (OAA) Amendments of 1975, The Omnibus Budget Reconciliation Act (OBRA) of 1981, and The Older Americans Act Amendments of 2000.

Today, more than 3,500 adult day services programs serve more than 150,000 Americans each year. While this number is impressive, it is not sufficient; almost 5,500 new programs are needed to meet current demand. Thirty-nine percent of adult day programs are open 10 or more hours on weekdays, while others also hold weekend hours to meet the needs of working caregivers.  

The main sources of reimbursement for adult day services are the Medicaid 1915(c) Waiver, OAA Title III and Title IV funds, Social Services Block Grants, the U. S. Department of

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Veterans Affairs and private payers. Expansion of Medicaid coverage and regulation since 2002 has also increased the amount of skilled and specialized services offered by adult day programs. Yet, reimbursement levels for adult day have not increased enough in most states to cover the costs of adding these skilled services. As a result, many adult day programs are struggling financially. In 2000, 44 percent of these programs reported a budget deficit.\(^4\)

The daily reimbursement rate for adult day, including the cost of transportation, can range from $32 per day in Texas to $141 per day in Vermont.\(^5\) The high cost of transporting clients to and from the adult day service site represents a significant part of the average reimbursement rate in most states and a major barrier to the expansion of adult day services, according to a 2007 study by the University of Iowa School of Social Work.

Other barriers to the availability of adult day services in Iowa include poor legislative support for this HCBS option, limited knowledge of adult day services among local health and social service professionals, and a tendency for these professionals to refer clients to adult day services too late. Researchers also found that different populations of participants resist attending the same adult day program, and that some older people stay away from adult day services altogether because of the stigma associated with attending “day care.” Finally, the report suggests that adult day programs have difficulty recruiting qualified staff and making sure administrators are knowledgeable about reimbursement and marketing. The high cost of certification and a dearth of adequate start-up funds also represent barriers to the development of adult day services, according to the report.\(^6\) A 2006 study by Partners in Caregiving for the North Carolina Department of Health and Human Services identified additional problems with adult day reimbursement, transportation and training of administrative staff.\(^7\) To improve the financial

\(^4\) Ibid.


\(^6\) University of Iowa School of Social Work. 2007. Adult Day Services in Iowa: Strengthening a Critical Home and Community-Based Service, report prepared for the Iowa Department of Elder Affairs.

viability of programs in North Carolina, researchers at Wake Forest University recommended a statewide public awareness campaign for adult day services, collaborative relationships between adult day providers and small business organizations, mandatory training for adult day services program directors and video conferences on funding issues.

**Home Health and Home Care**

Consumers and professionals alike have trouble differentiating between “home care” and “home health.” While many organizations and professionals use both terms interchangeably, there is agreement among many professionals that home health refers to a higher level of skilled care that is prescribed by a physician. Home health agencies provide private duty care, staffing registries, nurse practitioner services, durable medical equipment, pharmaceutical and infusion therapy, home care and homemaker services. Home care typically provides medication reminders, aid with activities of daily living, light housekeeping and transportation.

More than 9,000 Medicare-certified home health agencies served more than three million beneficiaries and made 103.9 million home visits in 2006. Approximately 11,000 home health agencies in the United States are not Medicare-certified. Medicare-certified home health agencies experienced a 55-percent growth rate from 2000 to 2005. This growth was more pronounced in certain states including Florida, where the number of agencies has doubled since 2000. Eighteen states experienced a decrease in agencies between 2002 and 2006.

Profit margins for home health agencies – which range from 27.2 percent for the top 25 percent of agencies to 2.3 percent for the bottom 25 percent – spurred the Medicare Payment Advisory Committee (MedPAC) to recommend a freeze on home health rates for fiscal year 2008. It should be noted, however, that MedPAC profit calculations did not include all home health costs, including those associated with dietary services, respiratory therapy, telehealth and marketing. Twenty percent of home health agencies have negative profit margins.

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Adding to the financial pressures facing home health is the “case mix creep” adjustment recently instituted by the Centers for Medicare and Medicaid Services (CMS). This administrative adjustment is expected to have a dramatic impact on reimbursement levels for home health programs, resulting in an 11-percent decrease in funding over the next four years. The adjustment is designed to account for what CMS considers to be increases in case-mix weight due to improved scoring on the Outcome and Assessment Information Set (OASIS). However, the adjustment does not account for the increasingly complex nature of the clinical care provided by home health agencies to clients who often have multiple chronic diseases.

The Balanced Budget Act (BBA) of 1997 required that all costs for Medicare home health services be reimbursed under a prospective payment system beginning in 2000. Before passage of the BBA, home health agencies were paid on a per-visit retrospective system for the services they provided. Eligibility and coverage criteria for Medicare home health benefits have not changed with the new rule. Nevertheless, the new requirement has served to limit access to, and slowed reimbursement increases for, home health.9

Medicaid spending on home health is projected to grow by 9.8 percent between 2007 and 2016. Yet, state-by-state variations in Medicaid rates and rules for home health remain a concern. New York’s Medicaid program, for example, pays higher rates for home health services than Ohio’s Passport program. In New York, 12- to 24-hour care is still covered by Medicaid while Ohio’s Medicaid system only covers one to two hours of care per day. Some providers will not participate in Medicaid’s home health program because reimbursement does not cover the expense of providing care.

**Hospice**

In 1965, Dr. Elisabeth Kübler-Ross made the case for treating dying patients at home in her seminal book, *On Death and Dying*. Kübler-Ross’s book had a tremendous impact on how

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people around the world viewed death, and her appearance before the U.S. Senate Special Committee on Aging in 1968 would affect U.S. public policy around death and dying for many years to come. After the hearing, hospice care was gradually incorporated into the nation’s long-term service and support system. A 26-site demonstration, launched in 1979 by the Health Care Financing Administration, assessed the cost effectiveness of hospice care and helped determine what a hospice is and what services it should provide. In 1982, Congress created a temporary Medicare hospice benefit, which became permanent in 1986. States were later given the option of including hospice in their Medicaid programs. In 2008, the Centers for Medicare and Medicaid Services began requiring that hospices have a quality assessment and performance improvement component.

There are more than 3,200 hospice programs across the country. In 2000, roughly 600,000 individuals – about one in every four Americans who died that year – received hospice care at the end of their lives.¹⁰ That care reduced Medicare expenditures during the last year of life by an average of $2,309 for each hospice user, according to a recent study by Duke University.¹¹

Some hospice programs are part of hospitals or health systems while others are independent, nonprofit agencies or for-profit companies. Typically, hospice teams offer care and support to those suffering from a variety of end-stage diseases and other illnesses deemed life-limiting. The care team usually consists of the patient's family and friends, who provide most of the daily care; volunteers; and professional staff who visit regularly to offer families training and support, monitor the patient’s medications and provide physical and medical care as needed.

The Medicare and Medicaid hospice benefits consist of two, 90-day periods followed by an unlimited number of renewable 60-day periods. Hospices will see a 2.5 percent increase in their payments in 2009. Unfortunately, this increase is 1.1 percent less than would have been the case if the Centers for Medicare and Medicaid Services (CMS) had not phased out the Budget Neutrality Adjustment Factor (BNAF) to the hospice wage index. The BNAF was instituted a

¹⁰ National Hospice and Palliative Care Organization. Online at: http://www.nhpco.org/templates/1/homepage.cfm

decade ago to help hospices maintain their financial viability during the transitional period after CMS switched to a new wage index. CMS maintains that phasing out the BNAF will save Medicare $2.18 billion over five years. However, the phase-out, which became effective Oct. 1, 2008, is essentially a rate cut that could be as high as four percent. The loss to hospice programs will be dramatic, especially considering the fact that the average profit margins of nonprofit hospices are less than 3.5 percent.

Additional fiscal pressures are also coming from the Medicare Payment Advisory Commission (MedPAC), which recently recommended that the hospice payment update be frozen. MedPAC has raised concerns about the 30-percent increase in lengths of stay for hospice patients from 2000 to 2005. The commission attributes this increase to changes in both the type of diseases being treated by hospices and the timing of the average person’s entry into hospice. Currently, more individuals are referred to hospice with an Alzheimer’s disease diagnosis than in previous years. These individuals stay in the hospice program for an average of 86 days, compared to a 44-day average length of stay for a lung cancer patient. The mean length of stay for hospice in 2005 was 67 days, an increase of two days over 2004.12

Increases in the share of non-cancer diagnoses among the hospice population and changes in the care of cancer patients has also had an impact on hospice costs.13 A 2004 RAND Corporation study reported that care-related expenses were four percent higher during the last year of life for hospice patients than for those receiving traditional medical care. In addition, patient care for non-cancer hospice patients was more expensive than Medicare Fee-for-Service. However, the report also revealed that hospices can provide a 17-percent savings to Medicare for patients with certain types of cancer.14


While the number of hospice patients is increasing, they still represent a relatively small percentage of dying patients. Only 24.9 percent of Americans died at home in 2002, even though 70 percent of Americans surveyed by the Robert Wood Johnson Foundation (RWJF) expressed a desire to do so. This lack of adherence to patient wishes at the end of life could be prevented if more Americans had an advance directive in place. States can help promote advance directives by adopting extensive and more uniform procedures to ensure that hospital patients are educated about appropriate options for end-of-life care, including hospice services, home health services and Programs of All-Inclusive Care for the Elderly, when appropriate. States could model their advance-directive initiatives on successful initiatives in Oregon and Maine. In addition, important lessons can be learned from a nationwide, RWJF-funded communications campaign called “Last Acts.” The campaign, which ended in 2005, educated consumers and health professionals about end-of-life care, with a particular emphasis on the importance of advance directives.

Housing with Services

A growing number of congregate housing settings have become de facto long-term care settings for many low- and moderate-income seniors with declining health and increasing levels of frailty. Unfortunately, uncertain funding for both supportive services and rental subsidies jeopardizes the ability of housing-with-service options to fulfill their potential as key components of our nation’s long-term care continuum.

The AAHSA Housing Cabinet is now exploring creative ways to bring health and other supportive services to senior housing. One strategy calls for the use of low-income housing tax credits to encourage the development of senior supportive housing projects that offer a minimum level of services. Supportive and health-related services offered within these projects would continue to be provided by existing HCBS programs that are funded through the Older Americans Act or Medicaid waivers. The Housing Cabinet is also exploring strategies that would

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utilize traditional HCBS funding mechanisms to provide a more predictable revenue stream for needed supportive services in senior housing.

The HCBS Development Cabinet discussed many housing-with-service options during its months of deliberations. These include:

- **Assisted living in congregate housing.** Connecticut provides this option in state-funded congregate housing, federally-financed HUD complexes and private-pay assisted living facilities. (See Appendix A for more details.)

- **Continuing care and HCBS.** Some Continuing Care Retirement Communities (CCRCs) offer home care, home health and adult day services to residents and non-residents. Through the “CCRC without Walls” and “CCRC Live at Home” models, older people living in their own homes pay a membership fee and receive a package of services.

- **Intergenerational housing.** The U.S. Census Bureau and the U.S. Department of Housing and Urban Development (HUD) recently explored how HUD assisted housing programs could meet the affordable housing needs of eligible intergenerational families, including grandparents raising grandchildren. Funding for this housing has been limited, however.\(^{16}\)

- **Shared housing.** Through shared housing, two or more unrelated people live together in a home or apartment. Each person has a private room and shares the kitchen, dining room and other common areas.

- **Cohousing.** In cohousing communities, individuals live in their own housing units but share common facilities and participate in group decision making and community management.

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Only one cohousing project for older adults has been completed and several projects are in development.  

- **Intentional communities.** Older adults living in intentional communities pay an annual membership fee to receive access to services, like transportation and home repair, which help them remain independent. Annual membership fees range from $500 to $1,200. Beacon Hill Village in Boston has pioneered this concept; similar communities are being developed in other states.

- **Naturally Occurring Retirement Communities (NORCs).** NORCs are geographic areas in a community where a large concentration of older people has “aged in place” in housing that was not originally built for seniors. Services in the country’s 80 NORCs are usually initiated by not-for-profit agencies and may include case management, adult day care, meals and personal care services. The *Community Innovations for Aging in Place Act of 2008* authorized funding for NORCs, but no money has been appropriated.

- **Housing cooperatives.** Prevalent in the Midwest, a housing cooperative is a resident-controlled business that uses its earnings and assets to help members age in place. Popular in rural areas, co-ops often provide transportation and home maintenance; some employ coordinators who help members obtain home and community-based services.

### Program of All-Inclusive Care for the Elderly

17 For more information about cohousing for seniors, visit Senior Cohousing. Online at:  
http://seniorcohousing.com/senior-cohousing-communities.htm

http://harvardmagazine.com/2008/01/aging-gracefully-at-home.html


20 United Jewish Communities. “NORC Aging in Place Initiative.” Online at:  
The Program of All-Inclusive Care for the Elderly (PACE) was developed to help frail older adults and older people with disabilities remain in the community. PACE organizations use capitated payments from Medicare, Medicaid and, to a limited extent, private payers to create a pool of funds that meet the needs of their participants. These funds allow PACE to provide all the care and services covered by Medicare and Medicaid, as approved and coordinated by a PACE interdisciplinary team. As a flexible model of care, PACE can also provide medically necessary care and services that are not covered by Medicare and Medicaid. There are 53 operating PACE programs in 25 states, serving about 16,000 individuals.

The all-inclusive component of PACE means that clients receive a coordinated package of care and services that combines primary and acute medical services with institutional and community-based long-term services like adult day care, in-home services, meals and transportation. While housing is not part of the PACE benefit package, many PACE organizations have developed partnerships with housing providers in order to maintain frail seniors in the community.

In 1985 and 1986, Congress authorized two separate budget acts that laid the groundwork for the PACE program. The *Consolidated Omnibus Budget Act of 1985* authorized the original demonstration project for On Lok, a PACE precursor that delivered long-term services and supports to people living in San Francisco’s Chinatown. The *Omnibus Reconciliation Act of 1986* authorized the PACE demonstration project to determine if the Medicare/Medicaid integration model used by On Lok could be replicated. PACE would not be authorized as a permanent Medicare/Medicaid benefit until 1997.

Despite their great potential to serve older people living in the community, PACE programs face several serious challenges, which require further research to identify workable solutions. These include:

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21 On Lok Health Services is a nonprofit organization established in 1971 in San Francisco. When On Lok hired Marie Louise Ansak to study the feasibility of opening a nursing home in the city’s Chinatown neighborhood, she found that the community’s older adults and caregivers wanted home and community-based options of care instead. Ansak outlined a system of care, modeled after the British Day hospital, which combined housing and all medical and social services. In 1979, On Lok received a Department of Health and Human Services grant to develop a consolidated model of delivering care to persons needing long-term care. In 1983, the organization received approval to test a new financing system that paid a fixed reimbursement each month for each person in the program.
• **Frailty factor phase out:** In the past, PACE programs received the same payment for every Medicare-eligible PACE participant. In 2004, however, the Centers for Medicare and Medicaid Services (CMS) began phasing in a new risk-adjusted methodology, called the Hierarchical Condition Categories (CMS-HCC), which pays PACE and other Medicare capitated programs a higher rate for enrollees whose care is likely to cost more. Until recently, a “frailty adjuster” allowed reimbursement rate-setters to include additional Medicare expenditures that might be necessary to care for a community-based, functionally impaired population. In 2008, CMS began implementing a new methodology for calculating the frailty factor component of PACE payments. This new methodology, which will be phased in over the next five years, could result in reduced Medicare payments for PACE.

• **Cuts in reimbursement for Medicare Advantage:** Current proposals being considered by Congress could reduce Medicare Advantage payments. Since PACE payments are tied to Medicare Advantage plans, reductions in Medicare Advantage payments will also impact PACE unless PACE is excluded from Medicare Advantage reductions.

• **State reimbursement rates:** No single methodology exists for the development of a Medicaid capitation rate for PACE, so each PACE provider must negotiate rates with its respective state. States differ in their approaches to rate setting, which adds to a lack of standardization in reimbursement rates from state to state.

• **No Medicaid mandates:** Because PACE is not a federally mandated Medicaid program, states can decide not to offer PACE or to limit its expansion.

**Legislative History**

The history of home and community-based services (HCBS) in the United States cannot be separated from the numerous legislative initiatives that have allowed providers to test innovative HCBS delivery systems and make successful options permanent. While much of HCBS-related legislative action has taken place in the U.S. Congress, the work of establishing and perfecting HCBS delivery takes place at the state level. For this reason, the final report of the HCBS
Development Cabinet contains numerous references to specific state programs that the cabinet believes can and should be replicated elsewhere in the nation. In addition, Appendix A presents a collection of best practices at the state level.

On the federal level, no legislation has been more influential than the Older Americans Act (OAA), which was signed into law on July 14, 1965. The act changed the face of aging services in this country, especially for older people living in their own homes. It established the Administration on Aging (AoA) and created 50 state units on aging that carry out OAA-funded programs. Subsequent amendments to the OAA, enacted in 1974, 1975, 1987, 2000 and 2005, have authorized funds to pay for homemaker services, transportation, adult day services, home care, home modification and transportation; provided consumer-directed and community-based long-term service and support options; and targeted services to individuals who are at high risk for nursing home placement.

Over the years, AoA and the Centers for Medicare and Medicaid Services (CMS) have worked together to foster choice in home and community-based services by helping older people in need of services make care decisions with a minimum of confusion. Since 2003, 43 states have participated in the Aging and Disability Resource Center (ADRC) Grant Program, an AoA/CMS initiative that helps states create a single, coordinated system of information and access for all persons seeking long-term services and supports. AoA also awards several grants that help senior centers, nutrition programs, senior housing projects and faith-based organizations implement evidence-based disease prevention programs.

**Nursing Homes and HCBS**

Over the past decade, federal funding of long-term services and supports has focused on “rebalancing efforts” that help states adjust their expenditure mix in order to increase their support for home and community-based services and reduce their reliance on institutions.

From 1998 to 2000, nine states used Nursing Home Transition Grants to identify and ease the transitions of nursing home residents who could move back into the community. The program’s
success rate was fair, but at least one program – the Arkansas Passage program – was successful. It allotted $1,600 for transition services to Medicaid beneficiaries who were living in nursing homes but did not require 24-hour care and whose community-care costs would not exceed what the state was spending on their nursing home care. Transition services included housing and utility deposits, first-month rent, home modifications, household items and durable medical equipment. Similar initiatives would follow in 2003 when Money Follows the Person grants allowed nine states to use transition coordinators to help nursing home residents move back to the community. The Nursing Home Diversion Modernization Grants program, which awarded $8.8 million in grants in 2007, is part of the AoA’s long-range vision to have every state’s long-term service and support system include nursing home diversion programs.

All of these grant programs illustrate the important role that targeted case management (TCM) can play in a state’s rebalancing process. TCM refers to a collection of activities that help individuals access needed medical, social, educational and other services. In 2000, CMS increased the federal reimbursement for TCM for institutionalized individuals to 180 days prior to their move back to the community.

Bipartisan support in Congress for reducing the “institutional bias” of long-term services and supports has increased in recent years. The Deficit Reduction Act of 2005 included a number of provisions to enhance the ability of older adults and people with disabilities to remain in the community. The bill expanded the number of rural PACE centers and created the 1915(i) state plan waiver, which removes a previous requirement that beneficiaries could only receive needed services at home if they would otherwise require institutional care. The waiver also allows beneficiaries to choose the kind of services they need as well as the agency or individual that will provide those services. Unfortunately, Iowa is the only state to receive a 1915(i) waiver to date; CMS is currently reviewing waiver requests from Colorado, Nevada and Georgia.

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22 Results varied from state to state. Only New Jersey (1,520 transitioned) and Michigan (12 transitioned) exceeded their goals. New Jersey’s program preceded the grant. Thomson Medstat, March 2003.


Creating Choice in Long-Term Services and Supports

In 1999, the U.S. Supreme Court affirmed the right of people with disabilities to receive services in the most integrated setting that is appropriate to their needs. The court’s influential decision in *Olmstead v. L.C.* launched a national effort to remove barriers to community living for 54 million Americans with disabilities. This effort, called the New Freedom Initiative, featured President George W. Bush’s 2001 Executive Order 13217, which called on the federal government to help states and localities swiftly implement the *Olmstead v. L.C.* decision. The order states that "The United States is committed to community-based alternatives for individuals with disabilities and recognizes that such services advance the best interests of the United States."25 The New Freedom Initiative increased access by people with disabilities to assistive technologies and to opportunities for education, homeownership, work, transportation and community life.

Creating an Infrastructure for HCBS

Since fiscal year 2001, the Real Choice Systems Change (RCSC) Grants for Community Living have helped all 50 states, the District of Columbia and two U.S. territories create an infrastructure that enables individuals of all ages to live in integrated and suitable settings and to exercise choice and control over their living arrangements and their care. Grantees in the $270.3 million program have focused on issues related to personal assistance services, direct service worker shortages, transitions from institutions to the community and respite service for caregivers and family members. They also have enhanced HCBS quality, improved processes for person-centered planning, created resource centers where consumers can obtain information about available services, and improved linkages between affordable housing and support services.26

Consumer-Directed Care

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Several Medicaid waivers support consumer self-direction in the provision of long-term services and supports. Ten states now have Independence Plus waivers, created in 2002 to promote person-centered planning and self-directed service options. In addition, a new 1915(j) waiver, authorized by the *Deficit Reduction Act of 2005*, allowed 15 states to establish Cash & Counseling programs that provide a flexible monthly allowance that recipients of Medicaid HCBS can use to make choices about the services they receive.

**New HCBS Options**

The Medicare Modernization Act of 2003 helped to promote two new vehicles that deliver home and community-based services in local communities. First, it created the Medicare Home Health-Medical Adult Day Program Demonstration Project, through which a certified home health agency is paid 95 percent of the Medicare rate for its own services and the services of an adult day health program. The program’s inadequate reimbursement for transportation and adult day services has created financial challenges for providers. CMS will submit a report to Congress after the demonstration ends in July 2009.

The Medicare Modernization Act also created the Medicare Advantage Special Needs Plans (SNPs), a new type of Medicare Advantage coordinated care organization that focuses on individuals with special needs. All SNPs must provide a model of care that includes appropriate provider/specialist networks; initial and annual assessments of individuals; a plan identifying goals, objectives and measurable outcomes; and an interdisciplinary care management team. SNPs rely on contracts with high-quality HCBS providers and physicians located in the areas where they have beneficiaries. Enrollment in SNPs grew from 532,000 in July 2006 to more than one million in September 2007.²⁷

Medicaid. Otherwise, a Medicare SNP contract cannot be awarded or expanded. From Jan. 1 through Dec. 31, 2010, existing dual SNPs that do not have a contract with the state Medicaid agency may continue to operate but may not expand their service areas. States are not required to enter into contracts with dual SNPs. To assure that the beneficiaries enrolled in SNPs receive the specialized care they need, all SNPs are required to have a model of care that includes:

- Appropriate provider/specialist networks.
- Initial/annual (re)assessments of individuals.
- A plan identifying goals, objectives and measurable outcomes.
- An interdisciplinary care management team.

Prior to enrollment, dual-eligible SNPs must provide a comprehensive written statement for each prospective dual-eligible enrollee. That statement must describe cost sharing protections and benefits to which the individual is entitled under the state Medicaid program. The new rule also expands the quality improvement program requirements for SNPs.

**Paying for Long-Term Services and Supports**

The *Community Living Assistance Services and Support Act (CLASS Act)* would establish a National Long-Term Care Insurance system that is critical for the future care needs of the Baby Boom generation. AAHSA continues to advocate for the CLASS Act and looks for progress on this critical piece of legislation in the 111th Congress.
Section III: RECOMMENDATIONS

The cost of providing both acute and long-term care is increasing each day and rising Medicare and Medicaid costs have experts wondering how long these systems can be sustained. The pressure on states to care for their aging population is overwhelming. It is hard to imagine how these pressures will be exacerbated as the older population grows in numbers and needs over the next three decades.

The Home and Community-Based Services (HCBS) Development Cabinet examined these financial realities as well as the clear preference of older consumers to choose for themselves the long-term service and support options that suit them best. The cabinet also recognized that older consumers will continue to demand high-quality, affordable and consumer-centered services that are delivered in their own homes whenever possible. After a year of research and deliberations, the cabinet proposed ways in which state and federal policy makers, as well as providers, could work together to create a coordinated long-term service and support system. That coordinated system should address the needs and preference of current and future consumers and feature home and community-based services as an integral component of service delivery.

The recommendations on the following pages, which represent areas of consensus among cabinet members, present a blueprint for reaching this goal. These recommendations call for:

- Developing a universal standard of quality for home and community-based care.
- Creating a finance system that promotes consumer choice and quality.
- Providing more long-term service and support options for Americans.

HCBS and the “Woodwork Effect”

The HCBS Development Cabinet identified a number of real and perceived barriers that stand in the way of more widespread HCBS availability. One perceived barrier – a theory commonly referred to as the “woodwork effect” – deserves special attention because it is often used to justify the exclusion of HCBS from cash-strapped public long-term service and support systems. The theory behind the “woodwork effect” is that if states provide more and better in-home
services for community residents who need skilled care, more people will “come out of the woodwork” to ask for services, thus placing an overwhelming strain on the Medicaid system.

The HCBS Development Cabinet does not believe that fears about a woodwork effect should deter states from expanding home and community-based services. On the contrary, the cabinet believes that the right HCBS system, carried out in concert with other service and support options, could improve the efficiency and cost effectiveness of long-term service and support delivery. A 2007 study by the Scripps Gerontology Center at Miami University supports this belief. The study showed that Medicaid utilization does not increase when an efficient HCBS system features a uniform, accurate assessment tool and a clinically driven case management structure.28

Researchers at the University of California San Francisco corroborated this finding with their study of the costs associated with mandatory inclusion of personal assistance services (PAS) under Medicaid. The researchers concluded that the inclusion of an “institutional level of need” requirement for PAS recipients – as well as the standard Medicaid income requirements – would limit the number of eligible participants and make PAS financially feasible.29

Both of these studies suggest that requiring HCBS recipients to have an institutional level of need will help expand consumer choice, provide for more efficient service and support delivery and serve the needs and preferences of consumers and their families.


Develop a Universal Standard of Quality
For Home and Community-Based Care

The HCBS Development Cabinet chose to place its highest priority on recommendations designed to ensure that no matter where an older consumer receives long-term services and supports – at home or in a residential care facility, in rural or urban areas, and in every corner of the nation – he or she can be assured of their quality. Providing these assurances will require a concerted national effort to ensure that quality standards exist in all settings, including HCBS programs.

The HCBS Development Cabinet identified several features that must be part of any high-quality home and community-based services program. First and foremost, services must be coordinated by a multidisciplinary team that includes the consumer’s primary care physician, HCBS providers, family caregivers and the older person who will receive care. These teams must use case management, electronic data systems and consumer-empowerment strategies to enhance communication and collaboration among team members and to involve consumers in managing their own health and health care.

The HCBS Development Cabinet believes firmly that the quality of long-term services and supports, today and in the future, will depend on the availability of a qualified and plentiful workforce as well as technologies that allow older people to remain independent for as long as possible while remaining safe, healthy and socially connected. It is critical that all levels of government, and all providers, invest today in strengthening the nation’s workforce and technology infrastructures. Only then can we be ready to meet the challenge of providing quality long-term services and supports to a growing older population for decade to come.
Enhancing Care Coordination

**Recommendation**

*Continue to encourage the federal government to make the Medical Home, and similar programs that follow the Guided Care model, a permanent part of the Medicare system. These programs should use care coordination and technology to coordinate primary, acute and long-term care services.*

The field of home and community-based services (HCBS) has no national standard of quality.\(^{30}\) As a result, the quality and level of care provided through HCBS varies from state to state. Quality initiatives cannot be 100-percent effective when only one provider type is involved in implementing and monitoring them. Rather, these initiatives must involve the collaborative efforts of all HCBS provider types. Only then can consumers be assured that the long-term services and supports they receive will meet consistent standards of quality no matter where they receive them.

Several models exist on which such a collaborative quality initiative could be based. For example, 150 hospitals, nursing homes and home care agencies participating in the New Jersey Hospital Association’s Pressure Ulcer Collaborative worked together for 22 months to devise common strategies to prevent pressure ulcers. Members of the collaborative shared the same goals and used the same assessment tools and procedures to achieve their goals. Together, they succeeded in reducing pressure ulcers by 70 percent.

The Medical Home is another example of collaborative efforts on the provider level that have helped older people manage their chronic conditions and avoid hospitalizations. A consumer’s Medical Home is centered in a primary health care setting, where a partnership develops between the patient, his or her family and the primary health care practitioner. These partners work together to access all medical and non-medical services the consumer needs. To promote coordination and continuity of care, the Medical Home maintains a centralized, comprehensive record of all health-related services.

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\(^{30}\) The nursing home industry follows a federal standard of care. Home health agencies follow standards of care established by the Joint Commission.
The Centers for Medicare and Medicaid Services (CMS) has shown interest in the Medical Home concept as a way to coordinate care for older people with multiple illnesses that require regular medical monitoring, advising or treatment. In January 2010, an eight-state Medical Home demonstration program will begin providing targeted, accessible, continuous and coordinated family-centered care to Medicare beneficiaries with chronic conditions.\textsuperscript{31} The Medical Home concept and its relevance to older people could also be advanced through the \textit{Independence at Home Act}, which is expected to be reintroduced early in the next Congress. The bill would provide various incentives that encourage health professionals to offer care options that afford their patients greater independence. It would establish a 26-state, three-year demonstration project designed to generate Medicare savings through a patient-centered health care delivery model that helps beneficiaries with multiple chronic conditions remain independent while reducing duplicative and unnecessary services, hospitalization and other health care costs.\textsuperscript{32}

A working example of the Medical Home concept can be found in The Guided Care program, developed at Johns Hopkins University in Baltimore, Md., to meet the growing challenge of caring for older adults with chronic conditions and complex health needs. At the center of the model is a Guided Care Nurse, who works with the older consumer’s primary care physician to assess the consumer and caregiver at home, create an evidence-based care plan, monitor the consumer’s condition, coordinate care transitions and promote patient self-management through coaching, education and access to community resources.\textsuperscript{33} A pilot study found that Guided Care resulted in greater consumer satisfaction and lower insurance costs.\textsuperscript{34}

\textsuperscript{31} Centers for Medicare and Medicaid Services. “Medicare Health Support Overview.” Online at \url{http://www.cms.hhs.gov/CCIP/}


\textsuperscript{34} Johns Hopkins Bloomberg School of Public Health. Online at: \url{http://www.guidedcare.org/}
Hospital at Home

Recommendation

Congress should create payment mechanisms to facilitate demonstration grants for Hospital at Home models of care.

Older people who live at home often experience adverse events in the hospital. Some of these consumers are so traumatized by their previous experiences in acute care settings that they refuse hospitalization altogether, forcing their physicians to patch together care plans under less-than-optimal circumstances. To remedy this situation, physicians from Johns Hopkins School of Medicine and the John A. Hartford Foundation created the Hospital at Home.

Patients requiring hospital admission for certain chronic conditions are recruited for Hospital at Home in an emergency room or ambulatory site. Following evaluation, patients are taken home, where they receive hospital-level care until they are stable enough to be “discharged.” Care then reverts to the patient’s primary care physician.

The HCBS Development Cabinet believes that the Hospital at Home program deserves further study. Congress should authorize demonstration grants to test the program’s potential to reduce hospital stays and improve the continuity of care offered by home and community-based providers.
Data Tools That Improve Care

**Recommendations**

*Congress should pass legislation that encourages Medicare providers to use standardized data systems, such as the CARE tool, to increase communication and care coordination among primary care, acute care and long-term care providers and to ease transitions between different levels of care.*

*The federal government should give providers incentives to use electronic medical records and web-based care plans. Such initiatives as the My Shared Care Plan would improve quality and consumers’ involvement in their care.*

Standardized data systems – including assessment tools and electronic health records – can improve communication and coordination among health care providers and, in the process, improve quality of care and patient outcomes. These standardized data sets are being used in several innovative programs to improve the quality of care that older adults receive when they transition from the hospital to home.

Care Transitions in Communities, a new program from the Centers for Medicare and Medicaid Services, uses a standardized Continuity Assessment Record and Evaluation (CARE) tool to help Quality Improvement Organizations better serve seriously ill Medicare beneficiaries. The CARE tool uniformly measures and compares Medicare beneficiaries’ health and functional status across provider settings at critical times, including transfers.\(^{35}\) The online instrument, which will provide quality and payment information to Medicare, is being tested in 10 locations.\(^ {36}\)

Another program, called “Improving Transitions across Sites of Geriatric Care,” uses a patient-centered record to bolster an interdisciplinary approach to care. Coordinated by the University of Colorado Health Sciences Center, the comprehensive care program is designed to improve transitions among hospitals, skilled nursing facilities (SNFs) and home for consumers with

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During the transition period, the program’s nursing transition coach conducts a thorough assessment of the patient, guides and monitors the patient, helps the patient manage medications, and responds to any red flags that might arise. Two data systems help the transition coach carry out his or her job. A Medication Discrepancy Tool helps remedy transition-related medication problems. A personal health record (PHR) for each client includes that patient’s medical history, medication records, and a list of tasks that must be completed before the person returns home. In addition to managing each patient’s PHR, the transition coach conducts a follow-up visit to assess the home and develop a relationship with the patient.

Electronic medical records (EMR) can help enhance communication among members of an older consumer’s multidisciplinary care team. They also allow team members to work in concert with the consumer to carry out the care plan. For these reasons, the HCBS Development Cabinet would like to see primary care physicians, HCBS providers and older consumers utilize EMRs.

Another beneficial use of technology, called My Shared Care Plan, was designed for care planning by the Whatcom County Pursuing Perfection Project in Bellingham, Wash. The tool allows consumers to gather all health-related information in one place and to take an active part in managing their health care. Like most EMRs, the shared care plan contains the individual’s personal profile and information about diagnoses, medications, allergies and treatment goals. In addition, the plan contains the consumer’s self-management and lifestyle goals, action steps to meet those goals, and advance directives.

Patients with Internet access can store their shared care plan on a secure Web site and can give permission to others, including family members or providers, to view the record. In this way, every provider who treats the patient can have access to the shared care plan and all providers will have the same information about the patient’s health status and treatments.38

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37 Coleman, E. et al. (n.d.). University of Colorado Health Sciences Center Division of Health Care Policy and Research.

38 Institute for Healthcare Improvement. “Shared Care Plans.” Online at:
http://www.ihi.org/IHI/Topics/HIVAIDS/HIVDiseaseGeneral/Tools/My+Shared+Care+Plan.htm
Targeted Case Management

**Recommendation**

Congress should amend the regulation for targeted case management to ensure that chronic care management is reimbursed and that case managers have adequate time to coordinate services for an individual transitioning to the least restrictive living situation. The regulation should also ensure that older adults and persons with disabilities who are living in the community have access to comprehensive case management.

The Service Options Using Resources in a Community Environment (SOURCE) program in Georgia is an exemplary example of how case management can increase the effectiveness of home and community-based service programs. Individuals in the SOURCE program are assessed and placed in categories based on their risk of nursing home placement. The SOURCE Enhanced Case Management team then implements and evaluates “care paths” that promote quality care based on the individual’s diagnosis. This quality standard for care extends to all SOURCE care providers, including the individual’s physician, and in-home, adult day and personal support services. All SOURCE providers must follow the program’s quality guidelines in order to render services to Medicaid clients who are SOURCE participants.

The program seems to be working. In fiscal year 2004, the average monthly cost for nursing facility costs in Georgia was 96.9 percent higher than the cost of caring for an individual in the SOURCE program.39

In 2000, the Centers for Medicare and Medicaid Services increased the federal reimbursement for targeted case management for institutionalized individuals to 180 days prior to their move back to the community. This policy should be continued. In addition, the coordination of legitimate case management should be encouraged, not hindered. Case managers should determine eligibility and provide a pre-authorization for services in order to reduce the occurrence of a “woodwork effect.”

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Establishing Quality Initiatives for HCBS

**Recommendations**

The Centers for Medicare and Medicaid Services (CMS) should establish a standardized quality initiative for all Cash & Counseling programs. This initiative should include standards and competencies for human resources, training and evaluation. States should contract with home health agencies to train caregivers and complete evaluations for Cash & Counseling.

CMS should require that Special Needs Plans have eligibility requirements for enrollment, quality initiatives and a standardized benefit package.

Cash & Counseling programs place consumers in charge of choosing the home and community-based services (HCBS) they receive and the individuals or agencies that will deliver those services. Program participants receive a flexible monthly allowance to contract for Medicaid personal care services, purchase labor-saving devices or make home modifications that enhance independent living. Program staff offers counseling and assistance to help consumers manage their allowance and carry out their other care-management responsibilities.

Despite their prevalence in 15 states, there is no federal standard of quality for Cash & Counseling programs. These standards must be established. In particular, quality improvement initiatives should mandate criminal background checks for care workers, independent annual evaluations of program quality, and initial training for family caregivers participating in the program. The last two tasks could be carried out by home health agencies.

The HCBS Development Cabinet also recommends that Medicare Advantage Special Needs Plans (SNP) abide by enrollment criteria that reflect a more high-risk population. In addition, SNPs must offer a standardized benefit package to assure consumer choice. Foundations, as well as the federal government, should continue to promote Medicare/Medicaid integrated programs.
Addressing the Workforce Shortage

**Recommendation**

*Congress should mitigate the challenges posed by shortages in the long-term care workforce by enacting legislation that incorporates recommendations that have been developed by the Institute for the Future of Aging Services (IFAS). In the short-term, Congress should pass the Caring for an Aging America Act of 2008 and the Home Health Services Job Training and Caregiving Act of 2008.*

It will be extremely difficult to offer future older people the ability to choose high-quality long-term services and supports unless a qualified and plentiful workforce is available to provide those services. Unfortunately, the field of long-term services and supports is currently plagued by worker shortages that promise to grow more serious in the coming years as the aging population grows. The quality of home and community-based services depends on how successful we are in addressing our current workforce challenges.

The Institute for the Future of Aging Services (IFAS), a division of AAHSA, has worked for many years to identify workforce-related challenges and to propose solutions to address these serious shortages.\(^{40}\) The HCBS Development Cabinet endorses a number of IFAS recommendations, which include the following:

- **Track worker shortages.** A data infrastructure developed by the U. S. Department of Health and Human Services (HHS) and the U.S. Department of Labor (DOL) would be a helpful planning and policy development tool for states, municipalities and employers.

- **Channel workforce development funds to long-term care.** Use Workforce Investment Act and Temporary Assistance for Needy Families funds to recruit and train employees.

\(^{40}\) Institute for the Future of Aging Services. 2007. *The Long-Term Care Workforce: Can the Crisis be Fixed? Problems, Causes and Options.*

46
• **Tap new worker pools.** Encourage providers of long-term services and supports to focus their workforce recruitment efforts on labor pools that have been poorly tapped to date, including Hispanic Americans, African Americans, immigrants, individuals with disabilities, and people seeking part-time work.\(^{41}\)

• **Offer financial incentives, such as tuition subsidies or debt relief, to expand the labor pool.** The *Caring for an Aging America Act of 2008*, introduced by Sen. Barbara Boxer (D-Calif.), would accomplish this goal by providing loan repayments to nurses, social workers and others who provide geriatric care. The HCBS Development Cabinet supports this legislation.

• **Charge a federal-state work group with developing proposals to raise wages and improve workers’ benefits.** This group could explore the feasibility of implementing incentives, such as pay-for-performance, that address workforce issues.

• **Improve working conditions and job quality.** Specific strategies could include financial incentives and regulatory relief for employers and states that improve working conditions and reduce turnover; new DOL standards to improve worker safety; increased HHS support for programs that build leadership and management skills among professionals in the field; and a federal or state match for employer investments in workforce development.

• **Study the workforce preparation process.** Encourage the Institute of Medicine and states to examine the relevance of credentialing, education and training requirements for the professional and paraprofessional workforce.

• **Make significant federal investments in technology.** Develop, test and disseminate promising technologies that are designed to improve service delivery efficiency and reduce demand for hands-on care in both home-based and facility-based settings.

\(^{41}\) *The Home Health Services Job Training and Caregiving Act of 2008* (H.R. 6033), which was introduced by Rep. Nydia Velasquez (D-N.Y.), would help providers tap new employee pools by providing free training to public housing residents interested in becoming home health aides or personal care aides for older public housing residents.
• **Encourage consumer-managed care:** Fund new programs that enable older adults to manage more of their own care. Provide incentives and additional support to family caregivers so they can continue to shoulder the bulk of caregiving responsibilities.

In addition to supporting these IFAS recommendations, the HCBS Development Cabinet recommends that Congress pass legislation that would establish a permanent DOL-administered Geriatric Workforce Grant Program to help recruit nursing school professors and allow long-term care workers to repay the loans that financed their education and training.
Nurse Delegation

Recommendation
The federal government should provide Real Systems Change Grants to states that gradually implement and expand nurse delegation under their respective Nurse Practice Acts. States should initiate a nurse delegation system that includes consumer protection and workforce competencies.

In 1987, amendments to Oregon’s Nurse Practice Act allowed nurses to delegate to unlicensed persons a number of tasks that were formerly performed only by nurses. Delegation rules apply only to settings where a registered nurse is not regularly scheduled and is not available to provide direct supervision. Nurses can also delegate to lay caregivers in community-based settings, such as private homes and assisted living settings, as long as they follow designated safeguards.42

Washington’s Nurse Delegation Program was established in 1995, when the state legislature allowed delegation of six specific nursing tasks in community-based settings, as long as caregivers receive required training. A 1998 University of Washington School of Nursing study found that nurse delegation had improved care, enhanced consumer satisfaction and brought unlicensed and unregulated practice under the supervision of registered nurses. Washington is in the process of expanding its use of the Nurse Practice Act.43

The HCBS Development Cabinet recommends that other states be encouraged to follow the example of Washington and Oregon. Real Systems Change Grants should be used to encourage states to expand the tasks that can be delegated through Nurse Practice Acts.


Using Technology to Improve Quality

Recommendation

Congress should pass legislation that incorporates the recommendations of the Center for Aging Services Technologies (CAST) regarding how technology can improve quality in aging services and promote more efficient utilization of the long-term care workforce.

Technology has the potential to help all providers of long-term services and supports improve the quality of services they provide to older adults in a variety of settings. However, its potential to help providers of home and community-based services (HCBS) serve their clients is particularly exciting. According to the Center for Aging Services Technologies (CAST), a division of AAHSA, these technologies can:

- **Provide social connectedness.** Technology devices in this category can foster successful aging among older people living in the community. They include computer-based programs aimed at entertaining, offering physical stimulation or enhancing memory.

- **Keep older people safe.** These devices include personal emergency response systems (PERS) that bring help directly to the older person in the event of an emergency. PERS are particularly important for older adults, since medical intervention within the first 90 minutes after a fall, heart attack or stroke is critical for a good prognosis. For this reason, the HCBS Development Cabinet recommends that the cost of PERS be reimbursed by Title III Older Americans Act funds and Medicaid in all states.

- **Promote health and wellness.** Health and wellness technologies, particularly those that fall into the category of “telehealth” or “telemedicine,” could have the most dramatic effect on HCBS providers. Telehealth employs a combination of sensors, in-home monitoring equipment and communication devices that allow informal caregivers and health providers to track an older person’s ability to live independently; help professional caregivers coordinate the delivery of needed care and services; and give health care providers the information they
need to identify early onset of disease, prescribe appropriate interventions and monitor the efficacy of those interventions. 44

Many home care agencies and their clients are already using telehealth in community-based settings. Almost a fifth (17.1%) of the 976 home care agencies participating in a 2008 study by the National Association for Home Care & Hospice and Philips Home Healthcare Solutions use some type of telehealth system and most (83.9%) of those agencies say their clients accept the new technology. Almost half (49.7%) of the agencies reported that telehealth reduced their number of visits per patients and most (88.6%) said the services led to an increase in quality outcomes. 45

While these results are encouraging, inadequate funding for telehealth and other technologies remain a major challenge to its widespread adoption among HCBS providers. Currently, 27 state Medicaid programs provide at least some reimbursement for telehealth services. However, other states face serious budget constraints that prevent them from adding any new Medicaid coverage or services without solid cost and benefit data.

Other barriers to technology adoption include older consumers’ negative experience with and misconceptions about technology; the lack of financial incentives that could encourage consumers and providers to purchase or invest in technology; and a lack of consensus – due, in part to a lack of research – on the value of these technologies. Finally, the inability of different information systems to communicate with one another – referred to as a lack of “interoperability” – is another serious challenge to widespread adoption of technology, particularly electronic medical records. These records are only useful in coordinating care if every member of the consumer’s health care team can access them. 46

The HCBS Development Cabinet endorses a number of strategies, proposed by CAST, to increase the adoption of aging services technologies. These include raising awareness of technology’s benefits through a large-scale educational campaign; supporting research that proves the value of aging services technologies; keeping consumers at the center of efforts to design, market and provide training on how to use technology; creating an infrastructure that ensures interoperability; and encouraging Congress to provide incentives for various stakeholders to invest in technology. In addition, the cabinet would support any efforts to promote technology use by flexible service providers, including Programs of All-Inclusive Care for the Elderly, which combine social and medical services and have better alignment of incentives. The cabinet also supports pay-for-performance systems that provide incentives for home health providers and physicians to invest in technology as a way to improve quality.

47 Ibid.
Improving Quality in Adult Day Services

**Recommendations**

*Federal Real Systems Change Grants should be available to help states and adult day providers work together to develop a database of information on adult day programs and participant outcomes. This information could be used to conduct operational and clinical benchmarking and quality analysis. A consumer survey could also be included in this process.*

*The federal government should offer Real Systems Change Grants to states that have experienced reduced consumer access to adult day services. States should use these grants to offer technical assistance and training for adult day center directors.*

Reimbursement and utilization of adult day services have been negatively affected by the lack of up-to-date operational and quality data currently available about this important home and community-based service (HCBS) option. Inadequate funding has been a barrier to more widespread data collection among adult day programs. However, the HCBS Development Cabinet believes that a combination of funding sources could be used to increase the availability of data on which adult day service programs could base benchmarking and quality analysis. Foundation funding could be sought to help adult day programs begin the data-collection process; university researchers could assist with the data analysis.

In addition, annual training programs are critical to ensuring that adult day programs not only maintain quality, but remain financially viable. Such training would be particularly valuable for directors of adult day services in states where these services are limited.
Create a Finance System
That Promotes Consumer Choice and Quality

Older adults and people with disabilities who are not eligible for Medicaid have fewer long-term service and support choices. In many instances, this lack of choice results in expensive hospital stays and nursing home placements. Home and community-based services (HCBS), if they were covered by Medicare or private insurance, would allow the individual to avoid or delay the need for institutional care.

The HCBS Development Cabinet recommends and endorses several strategies to ensure that older people with financial needs have full access to a range of options from which they can choose the services and supports that best meet their needs. Its primary recommendation echoes AAHSA’s Long-Term Care Financing Plan, which calls for the establishment of a National Insurance Trust for Long-Term Care that would serve as a mechanism for universal coverage of critical long-term services and supports. The trust’s funds would be supplemented by Medicare and Medicaid, which should ensure that HCBS and other providers have the capital they need to offer services and to recruit, train and retain qualified staff.

In particular, the cabinet recommends a more equitable reimbursement system for adult day health services, a pay-for-performance system for home health care, increased reimbursement for mental health services, and improved funding for the transportation costs that are such a critical part of the HCBS delivery system.
National Insurance Trust for Long-Term Care

**Recommendation**

*Congress should pass legislation that would incorporate the recommendation, included in AAHSA’s Long-Term Care Financing Plan, to establish a National Insurance Trust for Long-Term Care.*

Our nation must establish a National Insurance Trust that would provide a minimum level of coverage for every older person needing long-term services and supports.

This National Insurance Trust would be financed by premiums, not by general tax revenues. An independent, federally chartered organization would manage the premiums, investments and payments. Benefits would be available regardless of setting. The dollar value of benefits would be tied to a person’s need for assistance with activities of daily living, including bathing, dressing and eating.

According to one AAHSA model, the National Insurance Trust would pay a benefit of $75 per day for long-term services and supports, and would drastically reduce the number of people required to spend down their assets in order to qualify for Medicaid. The plan would also provide more service and support options for the 87 percent of older adults who are currently not eligible for community-based care through Medicaid.

The trust’s benefits would not cover the cost of all long-term services and supports. Older people with very low incomes would continue to need financial assistance. Others might wish to purchase extra wraparound coverage to cover the full costs of care. Medicare benefits would continue to provide for more intensive medical and shorter-term needs. While future expected Medicaid costs would be reduced by the trust, Medicaid would still be needed as a safety net for people in financial need.
Improving Funding for HCBS Providers

**Recommendations**

*The federal government should provide Medicaid Transformation Grants to help states improve their systems for financing long-term services and supports.*

*All providers of home and community-based services must receive sufficient annual payment updates to assure that they have the capital to recruit, train and retain qualified staff, as well as implement best practices in care.*

As noted above, Medicaid would still be needed as a safety net even after Congress establishes a National Insurance Trust for Long-Term Care. To help the Medicaid program fill this role, the federal government should award Medicaid Transformation Grants to help states improve funding of their long-term service and support systems. Grant funds would cover the costs of convening a task force of consumers, providers, stakeholders and state officials to develop a financing system for long-term services and supports that promotes innovation and quality while ensuring that all providers receive adequate funding based on the number of consumers they serve.

Providers cannot initiate innovative programs, recruit and retain qualified employees or maintain a high standard of quality when their reimbursement rates are frozen or cut each year. A sustainable financing system must provide annual cost updates that adequately reflect increased transportation and workforce expenditures for home health and hospice. States must eliminate barriers that keep providers of home and community-based services (HCBS) from expanding their programs.

Finally, state efforts to reform the financing of long-term services and supports must recognize the shifting preferences of consumers. Clearly, more older adults now choose to remain in their own homes for as long as possible. While this shift in the location of care increases the demand for home and community-based services, it also means that nursing homes and assisted living
centers find themselves caring for a population with complex health conditions. Any financing strategy must address both the increase in demand for HCBS and increases in the complexity of care offered by nursing and assisted living providers.
Improving Medicare and Medicaid Coverage

**Recommendations**

The federal government should gradually expand the Medicare Home Health Pay-for-Performance Demonstration Program and give it permanent status in all 50 states after it has been determined that the monitors being used are true indicators of quality and cost-effective care. An efficient Pay-for-Performance Program for Medicaid home health services should be tested in states using federal demonstration project funds. The monitors used must emphasize qualitative and quantitative outcomes that occurred because of the home health agency’s care.

*Congress should increase Medicare reimbursement for mental health services. These services hold great potential for reducing emergency room visits and inpatient hospital stays, and improving outcomes for older adults with depression. The Medicare reimbursement for counseling should be increased to expand the supply of social workers providing counseling services.*

The home health industry has experienced a number of reimbursement changes over the past several years. Among those changes are the new Medicare home health prospective payment system and the Medicare Pay-for-Performance Demonstration. Despite the potential that these programs represent, however, the financing system for home and community-based services (HCBS) remains fragmented and does not meet the needs of older people who are eligible for both Medicare and Medicaid. The HCBS Development Cabinet believes that this dual-eligible population would be best served by a pay-for-performance funding system for home health care, funded by Medicare and Medicaid, which monitors quality and care costs.

In addition, Medicare must do more to address the mental health needs of the elderly, which are well documented. The U.S. Surgeon General reports that 37 percent of seniors in primary care settings display symptoms of depression that can be associated with poorer health outcomes and higher health care costs. Older people with depression are admitted to the emergency room for hypertension, arthritis and ulcers at nearly twice the rate of those without depression.48 Most

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sobering is the news from the American Psychological Association that older people account for 20 percent of all suicide deaths, the highest rates of any age group. Given these statistics, and the health-related implications of untreated depression, it is difficult to understand the disparity in Medicare reimbursement between psychiatric care and medical care. Lack of proper reimbursement means that older people do not receive the treatment they need until their mental illnesses become serious enough to require expensive inpatient care or institutionalization. This reimbursement policy increases the cost of care, deters mental health professionals from considering careers in geriatric mental health, and does a great disservice to older people who could benefit from timely treatment.


Improving Funding for Adult Day Services

Recommendations

The federal government should use Medicaid Transformation Grants to help states with an insufficient number of adult day service providers meet the care needs of older adults and persons with disabilities. Grantees should expand the number and scope of adult day services available by implementing acuity-based reimbursement systems for adult day services.

Congress should pass legislation that would provide coverage under the Medicare program, using the home health prospective payment system, for adult day health programs that provide skilled services.

Adult day health programs play an important role in state efforts to provide a variety of cost-effective long-term options to their citizens. To ensure that adult day health programs continue to play this role, states must design equitable and adequate reimbursement systems that allow programs to hire qualified staff, implement innovative programs and meet increasingly stringent state regulatory requirements. State reimbursement must reflect the increased level of clinical services now offered by adult day health providers – services that are required by state regulations. In addition, social model programs such as Senior Center Plus and Enriched Adult Day Services must be encouraged to follow strict eligibility criteria so that participants with medical needs are not shortchanged because they participate in a low-cost program that receives lower reimbursement.

State reimbursement policies must encourage the adult day provider to offer a level of service that would effectively reduce participants’ need for more expensive nursing home care. Systems that provide the same reimbursement for care, no matter what level of services are required by adult day participants, do not offer this encouragement. Unfortunately this one-size-fits-all reimbursement formula is the standard in most states. The Home and Community-Based Services (HCBS) Development Cabinet recommends that states, especially those that underutilize adult day services, be encouraged to establish an acuity-based reimbursement system for adult day providers. This system would base payment rates on the level of service that each adult day participant requires. The federal government could encourage adoption of acuity-based reimbursement systems.
based reimbursement by making Medicaid Transformation Grants available to states that are working to develop this type of system.

A replicable example of an acuity-based reimbursement system for adult day health services exists in Massachusetts, which provides three distinct levels of reimbursement based on the personal care needs of the individual. A basic level pays adult day health providers $46.89 for six-to-eight hours of adult day services; a complex level pays $58.66; and a health promotion and prevention level pays a rate of $27.32.\textsuperscript{50} States would be well served to examine this model and take steps to adapt it to their own reimbursement systems for adult day health programs.

On the federal level, the Medicare program should rely on HCBS providers to offer long-term services and supports in the most efficient manner possible. Medicare policy limits skilled services and rehabilitation to nursing care facilities and certified home health agencies. As an alternative, the cabinet recommends that federal legislation be introduced that would allow adult day health programs to apply for Medicare certification and receive payment through the home health prospective payment system. Policies and procedures that now govern Medicare reimbursement for home health – including the submission of clinical, quality and fiscal data to a federal database similar to the Outcome and Assessment Information Set (OASIS) used by home health providers – should also apply to adult day health.

\textsuperscript{50} Rhode Island Department of Elderly Affairs. 2006. “Multi-State Comparison of Adult Day Services.”
Improving Funding for Transportation

**Recommendation**

The federal government needs to ensure that reimbursement for transportation under Medicaid and Older Americans Act programs sufficiently covers costs. In addition, Congress should consider legislation that provides Medicare coverage for non-emergency medical transportation. The lack of available transportation to medical appointments is a leading cause of hospitalizations for older adults, especially those living in rural areas.

Transportation funded through Medicaid, the Older Americans Act (OAA) and Social Service Block Grants is an important part of the home and community-based services (HCBS) delivery system. If older adults have no transportation to adult day services or medical appointments, they will not receive treatments and services that enable them to remain independent at home. Unfortunately, transportation is poorly reimbursed by public payers, resulting in a shortage of transportation providers in particular geographic regions. Many providers cannot operate without sufficient funds to cover the costs of fuel, maintenance, vehicle insurance and drivers’ salaries and benefits.

The HCBS Development Cabinet recommends increasing Medicaid and OAA reimbursement levels for transportation providers, especially those operating in rural areas. In addition, Medicare coverage of transportation for non-emergency purposes, including medical appointments, is essential to ensure that older people who do not qualify for Medicaid will not experience interruptions in their care. Such interruptions can quickly lead to expensive emergency room visits or inpatient hospital stays.
Provide More Long-Term Service
and Support Options for All Americans

Choice cannot be a luxury that belongs only to the wealthy. Instead, all older Americans, regardless of income, deserve to have equal access to a variety of care options. The Home and Community-Based Services (HCBS) Development Cabinet is encouraged that federal policy makers are beginning to recognize the basic right of older Americans to choose what long-term services and supports they will receive and where they will receive them.

In particular, the cabinet supports recent initiatives – including The Empowered at Home Act of 2008, The Community Choice Act of 2007 and the Project 2020 program — which would expand HCBS programs and eligibility, especially for people who are at high risk for nursing home placement. The cabinet endorses efforts by the Administration on Aging to ensure that eligible older people know about their local long-term service and support options and possess enough information about those options to make informed choices.

The HCBS Development Cabinet recognizes how difficult it will be to address the need for more home and community-based services without addressing the parallel need for more affordable housing for older adults. The cabinet recommends several strategies that would help senior housing residents pay for the services they require and would also give housing providers the resources they need to offer critical meal, home health and adult day services on site.

Finally, the cabinet urges AAHSA members who offer housing and skilled nursing care to consider providing home and community-based services to their residents and to older people living in the surrounding community. Our efforts to increase long-term service and support options will only work if we also increase the number of providers who offer these options. In this regard, the HCBS Development Cabinet also supports state and federal legislation that increases, rather than limits, the supply of HCBS providers.
Increasing HCBS Options

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<th>Recommendations</th>
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<tr>
<td>Congress should enact the Empowered at Home Act of 2008, which would increase eligibility for home and community-based services.</td>
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<tr>
<td>Congress should pass the Community Choice Act, which would add personal care to the Medicaid State Plan.</td>
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<td>Caregivers need tax relief to help them with the financial burden of caregiving.</td>
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Bipartisan support in Congress for reducing the “institutional bias” in long-term care has increased. This willingness to increase the range of available service and support options is clearly illustrated by the Deficit Reduction Act (DRA) of 2005, which included a number of provisions to advance the ability of older adults and people with disabilities to remain in the community. In particular, the DRA created the 1915(i) state plan waiver, which removes a prior requirement that beneficiaries can receive needed services at home only if they would otherwise need institutional care. The DRA also allows states to empower Medicaid beneficiaries to make their own choices regarding the kind of services they need and from whom they will receive those services.

Unfortunately, only one 1915(i) waiver has been approved to date by the Centers for Medicare and Medicaid Services (CMS). Iowa’s new 1915(i) home and community-based services (HCBS) benefit became effective Jan. 1, 2007. CMS is currently reviewing waiver requests from Colorado, Nevada and Georgia.

The 1915(i) waivers differ from the existing 1915(c) and 1115 waivers in several important ways. First, 1915(i) waivers are considered an entitlement, meaning that all beneficiaries who meet the eligibility criteria must be served, with federal funds matching state expenditures. Second, services under the waiver cannot be based on the beneficiary’s need for institutional care. Instead, each state must establish needs-based criteria for the waiver that are less stringent than the institutional level of care for that state. Third, the rule for 1915(i) emphasizes “person-centered care,” which gives individuals an active role in developing their own care plans, and
“self-direction,” which allows individuals to take charge of their own services. The DRA also allows states to provide special services to individuals with chronic mental illness.

Unfortunately, eligibility requirements under the 1915(i) waiver are not as generous as existing waivers, which allow states to set eligibility at up to 300 percent of the Federal Poverty Level (FPL), using the income methodologies of the Supplemental Security Income (SSI) program. Instead, the 1915(i) waiver limits services to individuals on Medicaid whose income does not exceed 150 percent of the FPL. This low income eligibility level discourages states from applying for 1915(i) waivers and excludes a number of older adults needing care. Depending on the state definition of “community,” individuals residing in assisted living could also be excluded from receiving 1915(i) waiver services.

Lack of interest among states is a critical barrier to the introduction of more 1915(i) waivers. A state’s budget and its political environment – as well as spending limitations imposed by Taxpayer Bill of Rights laws – could affect a state’s willingness to apply for a 1915(i) waiver or a grant program that promotes choice in home and community-based services.

**Empowered at Home Act of 2008**

The *Empowered at Home Act of 2008* (S.3327), introduced by Sens. John Kerry (D-Mass.) and Charles Grassley (R-Iowa), would help overcome the eligibility barriers in the 1915(i) waiver. If passed, the bill would extend the waiver’s eligibility to 300 percent of SSI, the same level as existing waivers. The new bill would also eliminate limitations on the scope of services allowed under 1915(i) waivers, remove the state’s ability to limit the number of individuals who are eligible for HCBS, and provide federal grants to help states implement HCBS programs. In addition, the Senate bill would create a 1915(k) waiver that covers services and funding for individuals who are at high risk for institutionalization and not otherwise eligible for Medicaid under the state plan or an existing waiver.

The HCBS Development Cabinet is especially pleased with several features of the *Empowered at Home Act of 2008*. First, the bill extends spousal impoverishment protection to HCBS, thus promoting community living for individuals who require long-term services and supports. Spousal impoverishment protection for both income and assets should be extended to all HCBS
Medicaid waivers and state Medicaid plans. Area Agencies on Aging need more funding to educate the public about eligibility requirements for existing spousal protection regulations, as well as for Medicaid and Older Americans Act programs.

Second, the *Empowered at Home Act of 2008* would allow states to use Medicaid Transformation Grants to facilitate the training, recruitment, hiring, screening and fair compensation of direct care workers and to stabilize the HCBS workforce. The grant program, which would be extended for an additional two years with a funding appropriation of $150 million for each year, could also be used to help consumers find direct care workers and obtain the skills to direct their own care and financial resources.

**Community Choice Act of 2007**

*The Community Choice Act of 2007* would have a tremendous impact on promotion of home and community-based services. The bill, which has received limited support to date, would amend Title XIX of the Social Security Act to make community-based attendant care services an alternative for Medicaid recipients who are “institutionally eligible.” For up to five years, states would receive an enhanced Federal Medical Assistance Percentage match rate to cover both attendant care services and administrative activities that would help states develop their infrastructure for long-term services and supports. The bill would also provide system change grant funds to help states increase their ability to provide HCBS and create demonstration projects that evaluate service coordination and cost sharing for persons with disabilities who are eligible for both Medicare and Medicaid.

The HCBS Development Cabinet would like to see this legislation reintroduced in the future with more emphasis on aging and disability services. The cabinet recommends that any new versions of the bill include adult day health services – and not just personal care services – as a mandatory service under state Medicaid plans.

**Caregiver Support**

A frail older adult who has a family caregiver is five times more likely to remain at home. Given the potential of family caregivers to provide long-term services and supports, the nation must
establish a system to support these caregivers. One example of that effort is the *Alzheimer’s Family Assistance Act of 2007*, which provides a $3,000 tax credit to those who care for persons with Alzheimer’s disease or another chronic disease. The bill would also allow caregivers to take a tax deduction for long-term care insurance premiums.
Expanding Eligibility for Medicaid

Recommendations

The federal government should adopt a more reasonable standard to determine poverty, such as the Elder Index developed by the Elder Economic Security Initiative. This index should replace the Federal Poverty Level as a predictor of need.

Congress should pass legislation that establishes a Medicaid eligibility standard for individuals who are at high risk for nursing home placement.

Congress should pass legislation that uses an increase in the Federal Medical Assistance Percentage for Medicaid home and community-based services expenditures as a way to encourage states to institute presumptive Medicaid eligibility programs.

The federal government uses the 40-year-old Federal Poverty Level (FPL) to determine eligibility for most programs that provide home and community-based services (HCBS). The FPL is based on the cost of a food budget that meets minimum nutritional requirements, but it does not take into consideration regional or demographic differences that could affect the financial stability of a family or individual. Older adults who do not meet FPL-driven eligibility requirements for Medicaid, for example, may have needs that are not reflected in the FPL determination, such as their high medical costs or a higher cost-of-living in the region where they reside. Shut out of the assistance they deserve, these adults must often choose between basic necessities and medical services.

The HCBS Development Cabinet recommends that federal and state governments adopt a more accurate measure of poverty and need within a region, such as the Elder Index developed by the Economic Security Initiative (EESI).[^51] The Elder Index provides a more complete picture of the

[^51]: The Elder Economic Security Initiative (EESI) at Wider Opportunities for Women (WOW) is a multi-year project that offers a conceptual framework and concrete tools to shape public policies and programs to promote the economic well-being of older adults. The EESI combines coalition building, research, education, advocacy and a media strategy at the community, state and national levels. In its first year, WOW launched the project in California, Illinois, Massachusetts and Pennsylvania. The Elder Standard has been developed in conjunction with a national research partner, the Gerontology Institute at the University of Massachusetts Boston. For more information, visit http://www.wowonline.org/ourprograms/eesi/about.asp.
older person’s financial status because it is calibrated to household size, geographic area and life circumstances and is based on all costs older adults face on a daily basis, including housing, food, transportation and health care.

States should also be encouraged to establish a Medicaid eligibility category for individuals who are at high risk for nursing home placement but who do not meet Medicaid restrictions on assets and/or income. Wisconsin has created this category, which allows high-risk elderly to qualify for Medicaid-covered HCBS if the combination of their countable assets and six months of projected countable income is less than the cost of receiving nursing home care for six months in the region. The federal government should provide grants to help other states establish this category.

**Presumptive Medicaid Programs**

Coming home from a hospital stay is a critical time for an older adult or person with a disability. Placed at a disadvantage by the speed of the discharge process, the individual may have limited options when it comes to choosing long-term services and supports after a hospitalization.

Several states have established programs that speed up the Medicaid approval process for consumers who are about to be discharged from acute care settings and have not yet established their Medicaid eligibility. These programs of presumptive Medicaid eligibility are particularly important in delaying nursing home placement among these patients. All states can allow older consumers to use Medicaid services before the full Medicaid application process is complete. However, most states are unwilling to risk losing revenue if the individual is eventually found to be ineligible for Medicaid. On average, states using presumptive Medicaid eligibility lose about $100,000 each year.

The HCBS Development Cabinet believes that the cost of preventing or delaying a nursing home placement far outweighs any monetary losses incurred through presumptive Medicaid eligibility. The cabinet applauds states that have decided to institute presumptive Medicaid programs. (See Appendix A for state program descriptions.) In order to encourage additional states to adopt these programs, the cabinet urges the federal government to provide $200,000 worth of stop-loss
insurance to states each year. In addition, a small increase in a state’s Federal Medical Assistance Percentage would serve as a valuable incentive for states to implement this program.
Person-Centered Access to Information

Recommendations

Congress should introduce and pass legislation to implement the Project 2020 program, which expands Older Americans Act programs to help prevent nursing home placements.

The Administration on Aging (AoA) should encourage states to develop an accurate database that Single Point of Entry and No Wrong Door providers can use to give consumers information about all available long-term service and support options, including Programs of All-Inclusive Care for the Elderly and adult day services.

The AoA should establish a national training protocol for the staff of Aging and Disability Resource Centers (ADRCs), Area Agencies on Aging (AAAs), and 2-1-1 operators. This training should include information about the services offered by all providers of home and community-based services.

The AoA should attempt to ensure that conflicts of interest do not arise when working with ADRCs, AAAs, 2-1-1 operators and Single Point of Entry programs so consumers are aware of all available HCBS services and that all HCBS providers are receiving appropriate referrals.

Project 2020: Fulfilling the Promise of the Older Americans Act (OAA) aims to modernize the Aging Services Network’s role in the provision of long-term services and supports by advancing OAA-supported home and community-based services (HCBS). The legislative initiative, proposed by the National Association of Area Agencies on Aging and the National Association of State Units on Aging, would greatly expand the use of OAA programs, which currently serve only six percent of eligible older adults. The HCBS Development Cabinet recommends that AAHSA make advocacy for Project 2020 a priority as it seeks to obtain future HCBS funding.

Project 2020 would direct funds to implement: (1) person-centered access to information, including case management and referral services; (2) evidence-based disease management and

health promotion programs that empower older adults to take responsibility for their health; and 
(3) Enhanced Nursing Home Diversion Services, which would provide HCBS to people with low incomes but high assets, the so-called “pre-Medicaid” population. This revenue-neutral initiative has broad bipartisan support in Congress.53

The bulk of Project 2020 funding would go toward providing person-centered access to information. This component, designed to help 40 million older adults and people with disabilities in the first five years, would be similar to the Aging and Disability Resource Center (ADRC) and other single point of entry models that already exist in some states. These programs provide information, counseling and case management to help consumers make informed choices about long-term services and supports, including HCBS. Indiana discovered that it could cover the cost of these case management and referral services with the savings it realized by helping only five percent of ADRC users avoid nursing home placement.

The HCBS Development Cabinet supports these access programs and believes they are most successful when they provide a single point of entry. For example, an ADRC sponsored by the Virginia Department for the Aging has improved its information and referral system by creating a coordinated database that features a mental health screening, automatically flags certain clients for mandatory follow-up and provides links to Eldercare Locator and the local 2-1-1 information service.

Project 2020 would be implemented through the existing OAA infrastructure with funds flowing from AoA to State Units on Aging, Area Agencies on Aging and Title VI Native American Aging programs. The federal government would fund 75 percent of the cost for person-centered access programs and 85 percent of the cost for prevention and health promotion activities. Funds for enhanced nursing home diversion services would be awarded to states through competitive grants.

53 Project 2020 was tested by three separate actuaries, who concluded that the program is revenue neutral.
Databases of Long-Term Service and Support Options

The HCBS Development Cabinet is aware that Single Point of Entry approaches have both strengths and weaknesses as they attempt to help older people and their families locate needed long-term services and supports. As shown by the Indiana example above, this model can save state funds as it refers older people to services that are most appropriate for them. However, the cabinet believes that training and use of technology within these systems can be improved.

The HCBS Development Cabinet recommends, for example, that the AoA require ADRCs to use electronic databases that include information about all the providers of long-term services and supports within a region. ADRC personnel should receive standardized training that explains the services of each provider type in the region and how older adults with specific needs could benefit from particular services. Similarly, individuals who call the Eldercare Locator or a 2-1-1 service in their area should be able to obtain specific information about available care options. States can also improve access to information by creating a central Web site that features consumer reviews of local service providers and delivery systems featuring “clinical triggers” that focus resources on individuals who are at high risk for nursing home placement.

Conflicts of Interest

AAHSA members report that Single Point of Entry staff do not always refer the frail older adult to Programs of All-Inclusive Care for the Elderly (PACE) or adult day services, even though these older adults could benefit from the varied and coordinated care offered through these programs. The tendency to favor certain HCBS provider types – and to minimize referrals to other types of service providers – points to the critical need for education among Single Point of Entry staff. These personnel should understand enough about the array of services available through PACE and adult day services – and their eligibility criteria – to refer specific individuals to them. PACE and adult day providers have a role to play in this education process by making community “gatekeepers” aware of the services they offer.
Program of All-Inclusive Care for the Elderly

**Recommendation**

*The federal government should promote the growth of Programs of All-Inclusive Care for the Elderly (PACE) nationally as a way to increase PACE access for frail seniors who would benefit from comprehensive, coordinated and integrated care.*

The 53 Programs of All-inclusive Care for the Elderly (PACE) operating in 25 states have been successful in helping frail older adults and older people with disabilities remain in the community. Because PACE organizations assume the full financial risk for care, the program has built-in financial, quality and consumer choice incentives. For example, PACE provides preventive care as a way to avoid a more expensive level of care, such as a nursing home placement, down the road.

A large initial investment of $2 million to $4 million, and the financial risk of starting a PACE, has been a challenge for providers and a major barrier to the development of the program. The *Deficit Reduction Act of 2005* helped reduce some of this burden by providing stop-loss funding that reduced the initial start-up costs for 15 rural PACE programs. Similar federal and state assistance would go a long way toward making PACE available in more states.
HCBS and Senior Housing

**Recommendations**

AAHSA state affiliates will advocate for state governments to apply the Supplemental Security Income (SSI) Enhanced Benefit for Assisted Living to SSI-eligible individuals who reside in senior housing.

HUD should consider designating Personal Emergency Response Systems, nutrition supplements and incontinent briefs as eligible medical deductions for subsidized housing.

It is difficult to address the need for more home and community-based services (HCBS) without addressing the parallel need for more affordable housing for older adults. Together, housing and HCBS play a major role in helping older people remain independent. The shortage of affordable senior housing is a major cause of nursing home placement. Similarly, inadequate housing can pose a major barrier to implementing HCBS programs.

The HCBS Development Cabinet recommends several steps to enhance the availability of home and community-based services within senior housing. The cabinet recommends that the federal government:

- Extend the Supplemental Security Income Enhanced Benefit for Assisted Living to eligible residents in senior housing as a way to pay for meal programs.

- Provide demonstration grants through the Administration on Aging to help senior housing programs establish congregate meal sites and adult day service programs.

- Offer start-up grants to housing providers that implement on-site home care or adult day services.

- Award additional grant funds to housing facilities that offer free certification programs for personal care aides and home health aides who live in the housing community.
State governments should:

- Establish a “cluster care Medicaid rate” to be used for in-home services provided in Naturally Occurring Retirement Communities and senior housing.

- Increase the availability of all long-term service and support options, including cost effective and less restrictive options like assisted living. Unfortunately, most states have poorly funded assisted living Medicaid waivers. This situation limits the number of available providers.
Expanding HCBS among AAHSA Providers

Recommendations

In order to promote a constellation of service options for consumers, AAHSA and its state affiliates should encourage state governments and the federal government to promote legislation that would reduce the use of moratoriums on providers of home and community-based services.

AAHSA should encourage and assist members who operate Section 8, Section 202 and tax credit housing, continuing care retirement communities (CCRC) and nursing homes to investigate whether operating (or contracting with) an adult day service program, home care agency, PACE or clinic would fit into the organization’s long-term strategic plan.

AAHSA should encourage and assist CCRCs to serve older adults who reside in the community by establishing CCRC without Walls programs.

A shortage of providers in a particular region severely limits consumer choice in that area. For this reason, states should be encouraging providers of quality long-term services and supports to establish operations in locales with a high level of need for those services. Unfortunately, federal and state regulations tend to limit the supply of home and community based services (HCBS) providers. The Certificate of Need Process for home health and the elaborate and time-consuming process for home health Medicare certification have reduced competition and innovation at a time when both are critically needed. In addition, large for-profit home health and hospice providers are purchasing small agencies, further limiting consumer choice.

The HCBS Development Cabinet would support state and federal legislation that increases, rather than limits, the supply of HCBS providers. Such a move would provide older consumers with the services they need to remain independent and the choices they deserve.

In addition, the cabinet believes that AAHSA members who offer housing and skilled nursing care would benefit greatly from offering home and community-based services to their residents and to older people living nearby. AAHSA housing members could help their residents remain independent for longer by offering home care services or contracting with a home care agency to
provide these services. Any contractual arrangement should include provisions that assure quality and reduce residents’ care costs.

AAHSA nursing home members could offer home health services to help Medicare beneficiaries transition back to the community. Members might also combine these home care services with additional HCBS programs, including nurse practitioner and house call programs, staffing registries, durable medical equipment and geriatric care management.
Changing Recommendations into Reality

The Home and Community-Based Services (HCBS) Development Cabinet encourages AAHSA to use the recommendations in this final report to pursue one overriding goal: to increase consumer choices in long-term services and supports. Reaching this goal will involve advocating for new legislation at both the state and the federal levels. In addition, AAHSA must take several steps to increase the supply of HCBS providers by encouraging its members to institute new home and community-based services and expand existing programs.

First, AAHSA should continue to highlight the best practices of its HCBS members in its educational sessions.

Second, AAHSA’s HCBS staff should be available to help all AAHSA members develop strategic plans that include the provision of home and community-based services.

Third, AAHSA should encourage member-to-member partnerships that are aimed at providing a constellation of long-term service and support choices within every community in this nation. The possibilities are limitless as long as AAHSA members bring a spirit of collaboration and innovation to these ventures. For example, adult day services, home care and Programs of All-Inclusive Care for the Elderly could work together in senior housing. Home care and adult day services could operate within a continuing care retirement community. Hospice and home health providers could offer services within nursing care facilities. These partnerships should also include AAHSA business members, who could bring innovation, efficiency and resources to HCBS provision.

Convergence with AAHSA Values

Supporting the expansion of high-quality home and community-based services is not a new idea for AAHSA. First, the recommendations presented in this report reflect the agenda outlined in AAHSA’s Five Big Ideas, which emphasize quality, transitions, talent, finance and technology. Second, the recommendations are consistent with the Quality First Initiative, AAHSA’s philosophy of quality and framework for earning the public trust in aging services. Providers that...
meet Quality First guidelines have renewed their commitment to helping older adults live their lives to their fullest potential. They share the HCBS Development Cabinet’s mission to provide a constellation of long-term service and support options from which older consumers can choose what suits them best. Like the cabinet, Quality First providers emphasize consumer friendly information, consumer participation and consumer trust. These organizations, like the HCBS Development Cabinet, also focus on workforce as a key component of quality.

Making HCBS Recommendations a Reality
The HCBS Development Cabinet is committed to making sure that its final report becomes a blueprint for action to expand the availability of HCBS for older people. To meet this goal, cabinet members and AAHSA staff will work together – and with other related organizations – to promote a philosophy of aging services that centers on consumer choice. Cabinet members will have agreed to meet with members of their respective state associations to share the policy recommendations and best practices included in this document. AAHSA’s HCBS staff will develop materials that state affiliates can use to incorporate these recommendations into their advocacy agendas.

Encouraging the promotion of diverse and complex home and community-based services requires a multifaceted and multidisciplinary approach by a consortium of proactive organizations. The broader our advocacy base is, the more likely we will be successful in promoting availability, affordability and choice in long-term services and supports. Therefore, cabinet members and AAHSA staff will also work with AAHSA partners at the state and national levels to develop and obtain support for legislation that includes this report’s recommendations.

Conclusion
Clearly, promoting choice for older consumers is not a goal that belongs exclusively to Republicans or Democrats, liberals or conservatives. Choice is an American ideal. AAHSA and its members promote that ideal each and every day by providing the services people need, when they need them, in the place they call home. The HCBS Development Cabinet looks forward to
working with AAHSA members to preserve and promote choice by expanding home and community-based services.
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APPENDIX A: How States Promote Home and Community-Based Services

In studying the impact of state programs on the availability of home and community-based services (HCBS), the HCBS Development Cabinet cabinet consulted *A Balancing Act: State Long-Term Care Reform*, a 2008 report from AARP’s Public Policy Institute.\(^\text{54}\) The report notes that from 1999 to 2004, the number of HCBS participants increased in 43 states and declined in seven. During the same period, the number of nursing home residents declined in 23 states and increased in 27 states. A state’s success in rebalancing its expenditures for nursing home care and HCBS depends on a variety of factors, including the array of services offered; the state’s HCBS philosophy and health care funding infrastructure; the design of consumer eligibility, assessment and access systems; the degree to which health and long-term services and supports are integrated; and the state’s emphasis on consumer direction and quality improvement.\(^\text{55}\)

The final report of the Home and Community-Based Services Development (HCBS) Cabinet includes references to a variety of state efforts to promote HCBS. Several states have made headway in increasing HCBS options through initiatives that provide sustainable funding for more services, expand eligibility, integrate Medicare and Medicaid, promote patient-directed care and bring services into senior housing. Following is a description of some state initiatives.

**Providing Adequate Funding for HCBS**

- The *Connecticut* State Legislature is considering expanding the Money Follows the Person Demonstration Project by establishing a trust fund to finance long-term services and supports. Connecticut’s current program serves 700 Medicaid recipients and the new bill would authorize funds to provide services for another 5,000 people.

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\(^{55}\) The full list of factors affecting rebalancing include: the state’s philosophy about HCBS, the array of services offered, the state’s organization of responsibilities, the coordination of funding sources, a single appropriation or global budgeting, timely eligibility, a standardized assessment tool, single point of entry, consumer direction, nursing home relocation or transitioning, quality improvement for HCBS, and integrating long-term care services.
• **Pennsylvania** has increased funding of home-assistance programs that are designed to keep people out of nursing homes. The state has offered financial assistance to nursing homes that are willing to shift their focus to alternative types of care.

• Older adults and persons with disabilities in **Wyoming** will obtain the help they need to stay in their homes thanks to the state's new *Long-Term Care Choices Act*. The new law allows the state to administer a program through which older people who do not qualify for Medicaid can receive community-based services such as help with bathing, house cleaning or grocery shopping. Services will be priced on a sliding scale.

• Governor Tim Pawlenty of **Minnesota** recently signed an Omnibus Health and Human Services Appropriations Bill that provides $1.46 billion in new health-related spending for the next two years. The bill provides about $94 million to purchase support services for older people and people with disabilities. This legislation includes rate increases of four percent over the next two years for a wide variety of home and community-based services.

**Shifting Funds from Nursing Homes to HCBS**

• **Iowa** and **Nebraska** have both developed systems that help facilities convert nursing home beds to assisted living beds. In Nebraska, a nursing facility cash fund also helps nursing homes add adult day services.

• In 1996, **Vermont** changed its nursing facility reimbursement policies to increase funding for HCBS.

• **Texas** allows nursing home residents to use Medicaid funds for HCBS if the individual transitions to a community setting.

• In **Tennessee**, the *Long-Term Care Community Choices Act of 2008* changes the TennCare Medicaid program so it more evenly distributes $1.2 billion between nursing homes and HCBS providers. Before the new law was enacted, nursing homes received 98 percent of state funds for long-term services and supports.
In 1981, state officials in Oregon made a philosophical commitment to offer the state’s citizens long-term service and support choices that include HCBS. Oregon has followed through on its commitment by instituting a single, computerized assessment tool, a single budget and a single agency to oversee care of older adults.

**Presumptive Medicaid Eligibility**

- **Colorado, Kansas, Michigan, Ohio, Pennsylvania** and **Georgia** have implemented pilot and permanent presumptive eligibility programs.\(^5^6\)

- **Washington’s** Aging and Disability Services Administration developed a presumptive Medicaid process to expedite the process of obtaining home and community-based services.\(^5^7\) The Washington Fast Track program has been very successful in preventing or delaying nursing home placements.

- **Pennsylvania’s** Community Choice program operates seven days a week, 24 hours a day to assess long-term service and support needs and Medicaid eligibility for individuals needing care. **Pennsylvania** – along with **Vermont** and **Maine** – also increased the number of individuals eligible for Medicaid HCBS by increasing the asset disregard for individuals utilizing home and community-based services. **Vermont** has also been proactive in educating the community about the availability of long-term service and support options.\(^5^8\)

- **Nebraska’s** Waiver While Waiting program uses Social Services Block Grants to cover costs in case an applicant for Medicaid is found to be ineligible.

- **New Jersey’s** pre-admission screening for nursing home placement uses a designation of “track one” or “track two” to indicate a short-term or long-term stay in a nursing facility.

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\(^5^6\) Colorado discontinued its presumptive Medicaid program in 2001. However, the program successfully helped 60 percent of Medicaid-eligible people prevent nursing home placement after hospital discharge and saved $407,012 in one year. The Social Security Administration and state budget issues caused the program’s termination.


\(^5^8\) Kaiser Commission on Medicaid and the Uninsured. 2005. *Strategies to Keep Consumers Needing Long-Term Care in the Community and Out of Nursing Facilities.*
Person-Directed Care

- **Alabama** is the first state to receive federal approval to offer self-directed personal assistance services as a permanent feature of its Medicaid plan. Participants in the Personal Choices program can direct their personal care, homemaker, unskilled respite and companion services. They also can hire relatives to provide care and can use their service budgets to pay for items that increase their independence.

Housing with Services

- **Connecticut** provides the assisted living level of care in state-funded congregate housing, federally-financed HUD complexes and private-pay assisted living facilities. As of February 2007, 165 congregate housing residents were enrolled in assisted living. The development of 95 new congregate units with enhanced core services is underway. In 1998, Connecticut initiated the Assisted Living Demonstration Project to test the extent to which subsidized assisted living communities are a viable and cost-effective care option for frail seniors facing inappropriate nursing facility admission. The state applied for a Medicaid waiver to fund assisted living services and provided funding for the creation and ongoing subsidy of new affordable assisted living units. In 2000, additional legislation expanded assisted living services into both existing state-funded congregate housing for the elderly and federally subsidized elderly housing developments.  

Medicare/Medicaid Integration


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The program’s goal is to end the fragmentation of financing, case management and service delivery.

- **Minnesota** offers three managed care options for seniors: Minnesota Senior Care (MSC), Minnesota Senior Care Plus (MSC+) and Minnesota Senior Health Options (MSHO). MSC+ is mandatory for individuals over age 65. While MSC is not integrated, MSC+ features acute and long-term care integration that includes waiver services for the elderly and 180 days of skilled nursing facility (SNF) care. MSHO, a voluntary alternative to MSC+, includes Medicare and Medicaid, waiver services for the elderly, prescription drugs and 180 days of SNF care. It uses a single point of entry and offers care coordination for all beneficiaries. Providers bill one agency for this Medicare/Medicaid integrated program.

- The **New York** Medicaid Advantage Program offers dual-eligible beneficiaries who are 21 and older the option of voluntarily enrolling in an integrated Medicare and Medicaid program. This plan provides all Medicare services and certain Medicaid services, including most acute care services not covered by Medicare and a limited set of long-term services and supports. Participating plans must be both Medicare Advantage and Medicaid managed care plans. The Medicaid Advantage program, available statewide, enrolled about 3,800 dual-eligibles in March 2006.

- **Texas** Star+, a mandatory Medicaid managed care program in the Houston area, integrates delivery of all Medicaid acute and long-term services and supports, and also integrates Medicare services for some participants. The program covers most Medicaid recipients who are elderly or have disabilities. As of June 2004, Texas Star+ enrolled about 52,900 individuals, including people who are dual-eligibles and those who are not.

- The **Washington** Medicare/Medicaid Integration Program voluntarily enrolls dual-eligibles aged 65 years and older who live in King and Pierce counties. The Centers for Medicare and

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90 The Medicare/Medicaid Integration Program (MMIP), established in 1996, has programs in 14 states. For more information, visit the Center for Health Policy Research and Ethics at George Mason University. Online at http://healthresearch.gmu.edu/MMIP/index.html
Medicaid Services (CMS) pays Evercare Premier™ the capitation rate for Medicare services, and the state pays the Medicaid capitation payment for those Medicaid services not covered by Medicare, including long-term services and supports. The state expected 600 to 1,000 individuals to enroll in this project.

- The Wisconsin Partnership Program (WPP) operates a voluntary integrated Medicare and Medicaid project that covers most acute and long-term care Medicaid services and all Medicare services. The WPP has four sites serving six counties and provides services to older adults and individuals with disabilities who require the level of care needed in a nursing facility. As of February 2006, WPP enrolled about 1,900 individuals.

- The Arizona Health Care Cost-Containment System (AHCCCS) operates a statewide mandatory managed care program for most Medicaid beneficiaries. A separate component of AHCCCS, called the Arizona Long-Term Care System, is designed for those who qualify for long-term services and supports. To improve care coordination, Arizona required that a managed care plan either become Medicare Advantage Special Needs Plan (SNP) or have a formal relationship with a Medicare Advantage or Medicare Advantage SNP organization.

- Through the Massachusetts Senior Care Options, Medicaid beneficiaries aged 65 and older can voluntarily enroll in a managed care plan through which they receive all of their Medicare and Medicaid services. CMS permitted the state to calculate the Medicare capitation payment using the same methodology employed by Programs of All-Inclusive Care for the Elderly. A frailty adjuster is applied to account for the increased level of impairment among enrollees. The Massachusetts project is transitioning to the standard Medicare Advantage payment methodology, which does not include a frailty adjuster.\(^{(61)}\)

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\(^{(61)}\) Congressional Research Service. 2006. *Integrating Medicare and Medicaid Services through Managed Care.*
APPENDIX B: How AAHSA Members Promote Home and Community-Based Practices

Center for Elders Independence

_Oakland, California_

In 1994, the Center for Elders Independence (CEI) established its second Program of All-Inclusive Care for the Elderly (PACE) center on the ground floor of a 144-unit affordable independent senior housing facility in San Pablo, Calif. This may be the first time PACE services have been combined with senior housing, thus offering a virtual continuing care retirement community for low-income older people. The San Pablo center was funded with tax credits and included a lease-to-own arrangement for CEI.

In 2000, CEI established a third PACE center, which was co-located with 40 units of HUD 202 housing and an outpatient geriatric clinic in Berkeley. In an innovative move, HUD funded the housing and Cal-Mortgage, which administers the California Health Facility Construction Loan Program, funded the health facilities. The deal was structured so that both funding entities could have a first security position. This was the first time that HUD worked successfully with a health services funder on a commonly occupied building. Now the concept has been replicated across the country.

Seniors’ Resource Center

_Denver, Colorado_

Seniors’ Resource Center offers non-medical, in-home care services, adult day and respite services to more than 12,000 clients at five fixed locations in the west Denver metropolitan area. Its transportation services provided more than 171,000 rides in 2007. Job training and care navigation programming assists older adults with long-term professional, financial and caregiver planning. The center also specializes in programs that benefit residents of rural and foothills communities located west of Denver.
The center’s launch of a new coordinated care model of service delivery in 2005 led to a series of new foundation-supported, private-sector partnerships to identify and respond to the unmet needs of vulnerable seniors living in the community. These include the following:

- A Safe in Your Space program, established in 2006 with Exempla Lutheran Medical Center, offers community-based education for the prevention of injurious falls affecting seniors in the home. The local hospital refers vulnerable patients to Seniors’ Resource Center, which relies on volunteers to arrange the installation of wheelchair ramps and bathroom grab bars. Corporate donors – most notably, Lowe’s Home Improvement Stores – provide supplies.

- Senior Reach used a federal grant to train more than 1,400 community members, who work with three nonprofit mental health organizations to recognize signs of depression and other mental and emotional health conditions among older people in the community. These symptoms often go unidentified and understated in this population.

- A full-time Community Navigator works in a 17,000-patient internal medicine practice to identify and refer seniors who have non-medical needs. The program recognizes that physicians often find themselves helping older patients address problems that could be better resolved in a community-based setting.

**Adult Well-Being Services**

_Detroit, Michigan_

Adult Well-Being Services provides respite services to caregivers of seniors and adults with developmental disabilities. The organization uses the self-determination model, which means that the caregiver selects the respite provider. Caregivers can select in-home or institutional respite, or can ask family, friends or others to provide respite care. They can reserve respite hours in advance for vacations or can receive respite on short notice to attend church or run errands. The response to this service has been overwhelmingly positive. Caregivers often mention respite as one reason they are able to continue in their caregiving roles.
In addition to respite, Adult Well-Being Services offers caregiver support groups and education. Caregivers have expressed the desire to meet with other caregivers in similar situations. In response, the Adult Well-Being Services recently established caregiver support groups for spouses, dementia-specific groups and other groups that bring together caregivers with common characteristics. The organization also offers phone and e-mail support groups for those who are unable to attend meetings outside their homes.

**CovenantCare at Home**

*Chicago, Illinois*

This Medicare-certified home health and private duty home care agency, sponsored by Covenant Retirement Communities (CRC), provides support and services to enable older adults to remain safely at home. Services include geriatric care management to residents who live on CRC campuses and seniors who reside in the neighboring communities.

**Christian Care Centers, Inc.**

*Mesquite, Texas*

Christian Care Centers, Inc. operates licensed and certified home health, hospice and personal care services for residents that live on three campuses in Texas: Christian Care Center of Mesquite, Lakewood Retirement Village of Ft. Worth and Hilltop Haven Retirement Community of Gunter. The organization also provides services and support to clients in Colin, Dallas, Grayson, Henderson, Kaufman, Johnson, Rockwall and Tarrant counties.

**Northern California Presbyterian Homes & Services**

*San Francisco, California*

Northern California Presbyterian Homes & Services (NCPHS) offers community service programs to more than 3,500 older adults throughout the San Francisco Bay area. NCPHS serves residents of its own communities and seniors who live outside those facilities.

A Nutritious Meals Program subsidizes the delivery of a daily hot meal for low-income seniors living in NCPHS’s two San Francisco HUD communities. The meals are nutritionally balanced
to aid in health maintenance and are served in a congregate setting, which helps to bring seniors together and reduce their isolation.

Through a Living at Home Program, social workers help seniors in the community remain independent in their own homes through access to available health, financial and other services. Services are offered in HUD subsidized communities, San Francisco Housing Authority properties and through a Meals on Wheels Program.

Through a WellElder program, a registered nurse serves as an on-site health educator at four HUD communities in the San Francisco Bay Area. This educator provides one-on-one consultations and health assessments; advocates for residents with their doctors, insurance providers, pharmacies and other health services; refers residents to community medical services; reminds residents about taking prescribed medications; and offers on-site classes and group programs relating to health issues, medical costs and insurance resources.

The NCPHS Senior Companion Program pairs senior volunteers with homebound or disabled adults living in Marin County. The Experience Corps program places Marin County senior volunteers in schools that support children under 18 years of age who have special physical, developmental or learning needs. Finally, the NCPHS Retired and Senior Volunteer Program places more than 1,100 senior volunteers in over 100 sites in San Francisco and Alameda County.

**Senior Independence**

*Columbus, Ohio*

Senior Independence is the home and community-based services division of Ohio Presbyterian Retirement Services (OPRS). It offers home health, home care, hospice, service coordination, health and wellness clinics, caregiver support, senior centers and many other home and community-based services. Senior Independence serves more than 50,000 people a year in 38 Ohio counties, and also sponsors a Web site for family caregivers.
Presbyterian Communities and Services

Dallas, Texas

Since it was founded in 1962, Grace Presbyterian Village has developed a reputation for excellence in senior care. Grace prided itself on providing exceptional care and services for seniors from full independence to the final stages of skilled nursing care. It met all of its residents needs with one exception – hospice care. At the end of a resident’s life, outside service providers took the lead on hospice/palliative care, often with less-than-satisfying results. After many years of frustration with the hospice care provided by the for-profit providers in its market, Grace decided to establish Faith Hospice (now Faith Presbyterian Hospice) in 2003. The hospice serves 120 patients in the highly competitive Dallas-Ft. Worth metropolitan area, where 80 other hospices also operate. Grace Presbyterian Village and Faith Presbyterian Hospice merged with Presbyterian Village North in May of 2008 to create Presbyterian Communities and Services. In 2011, the organization will open the first stand-alone hospice in-patient center in Dallas.
ABOUT AAHSA

The members of the American Association of Homes and Services for the Aging (www.aahsa.org) serve as many as two million people every day through mission-driven, not-for-profit organizations dedicated to providing the services people need, when they need them, in the place they call home. Our 5,700 members offer the continuum of aging services: adult day services, home health, community services, senior housing, assisted living residences, continuing care retirement communities and nursing homes. AAHSA’s commitment is to create the future of aging services through quality people can trust.