Richard “Dick” Ladd, founding director of the Oregon Division of Aging Services, is an icon for home- and community-based services (HCBS). With steadfast vision, strategic program-building skills, and an awesome grasp of data, he demonstrated that HCBS were possible for elders with substantial disability levels.

Dick joined the navy at age 18, serving on a submarine. During 1961 to 1975, he had various jobs, including a stint as a long-distance truck driver—a job through which he gained a precise understanding of United States geography, knowledge he retained while re-tracing the nation’s roads in outsized rental vehicles to promote HCBS. He earned a bachelor’s in experimental psychology and statistics in 1976 and a master’s in adult education and political science the next year. Dick rose meteorically in Oregon state government—in 1982 starting the first HCBS waiver. In 1992, he became Commissioner of the Texas Health and Human Services Commission, coordinating eleven agencies with a combined budget of $12 billion. His obituary in Salem, Oregon’s Statesman Journal said:

...through his innovative approach, Oregon was able to serve more people in need of long-term care, with a full array of services directed toward preserving the dignity and quality of life of those served.... He proved he could change bureaucracies and bring special interests and politics together for the good of the most frail and needy citizens.

After 1994, as director of Ladd & Associates (“The associates are my wife and our three gray hounds,” Ladd said), he wrote detailed analyses of long-term services and supports (LTSS) systems for eight state governments and consulted to many
others. From 1995, he co-directed the National LTC Balancing Project at the University of Minnesota, using data to highlight discrepancies between nursing homes and HCBS expenditures for older people. In his blunt state ratings, he didn’t hesitate to identify those making “poor” or “very poor” progress in rebalancing LTSS systems toward HCBS.

Dick tirelessly busted myths: that older people hold safety as their paramount life goal; that shared rooms in nursing homes provide appreciated companionship; that credentialed professionals can accurately determine an “appropriate” care level for people, thus prescribing where they should live; and that licensed nurses must do most homecare tasks. Dick advocated against the goal of a continuum of care along which older people are slotted, advocating instead for a repertoire of services from which people could select.

Dick articulated three barriers to widespread HCBS for older people: logistical, political, and philosophical; he thought the last the most formidable. His hallmark program included combining state funding and authority for both HCBS and nursing home care; developing assessment and case management systems; permitting the delegation of nursing tasks to unlicensed personnel; aligning programs for older and younger people; developing senior advocacy constituencies; and creating capacity for livable group-residential alternatives.

Many contributors to this issue of Generations still hear Ladd’s voice. Keren Brown Wilson says he spurred her to go national with her assisted living ideas at the risk of losing control of developments rather than “feeling good” about a rarefied program in Oregon. Susan Reinhard recalls him as “a mentor and cheerleader for those who sought to bring independence, dignity, and choice to their states.” Herb Sanderson, who considered Dick “a giant with a lot of us standing on his shoulders,” says his favorite Ladd quote is: “I never met a provider that had enough money or a bureaucrat that had enough staff.” Richard Browdie remembers him as a realist: “He knew that there was only so much money around, and that moving it would be hard. Dick accepted from the earliest days that changing the way the system treated older people was going to lead to conflict with the vested interests that benefit from the status quo. When confronted by those interests, he fought the good fight, usually winning and occasionally not.... He was a formidable, capable, and principled advocate for the right of older people to be able to choose the setting of their care as much as younger people with disabilities.”

Dick Ladd was a savvy insider, a no-nonsense spokesperson, a planner, and a visionary. He did not let the perfect be the enemy of the good. A larger-than-life figure, literally and symbolically, Dick was a man of thought and of action. If not for his premature death, he would still be trying to make our LTSS systems better and expand HCBS for everyone, including older people.

—Rosalie A. Kane, Guest Editor
Generations is the quarterly journal of the American Society on Aging. Each issue is devoted to bringing together the most useful and current knowledge about a specific topic in the field of aging, with emphasis on practice, research, and policy.

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30 Years of HCBS: Moving Care Closer to Home

Our Guest Editor
Rosalie A. Kane

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HCBS: The Next Thirty Years
By Robert L. Kane and Rosalie A. Kane
Thirty years have passed since the HCBS waiver program was first enacted. To mark this milestone in the evolution of home- and community-based services (HCBS), this issue of Generations (guided by our Guest Editor Rosalie A. Kane) looks at those decades of working toward a care system that aims to put people—and their quality of life—front and center.

Some might say that progress has been glacial, and driven substantially by a push for cost efficiency. But the HCBS waiver program, established within the 1981 Omnibus Budget Reconciliation Act and blended into the Social Security Act (Section 1915c), was an important step toward ensuring that elders (and people with disabilities) realize a good quality of life: all concerns about costs notwithstanding, individuals needing long-term services and supports (LTSS) might be better served outside an institutional setting. They could remain at home and in community, thus preserving independence and links to family and friends—and with a price tag more reasonable than the cost of institutional care.

On the occasion of HCBS’ thirtieth anniversary, where do we stand? Kane feels that “since 1982, ‘we’ve come a long way, baby’ in making HCBS available, and that we’ve learned from younger disability communities along the way.” But, she adds, “We have miles to go before we sleep. HCBS is still not the norm for older people needing LTSS.”

We are honored to have Kane as our Guest Editor: she is a tireless advocate who has, over the past decade, spent most of her time “trying to learn how to best create the conditions that allow older people to receive services and care at home—or in residential settings with services that have the hallmarks of home.” Her other focus has been on working for change in nursing home culture “in order to foster high-quality individualized, resident-centered care and services.” She wants to flip the paradigm so that HCBS is the norm and nursing homes the alternative, but quality in the remaining nursing sector is also vitally important.

“I am passionate about these agendas, but especially about promoting HCBS. My parents stayed in their own home until their deaths—my mother at age 89, and my father at age 102. My mother had Alzheimer’s Disease, and my father was blind due to macular degeneration. I am convinced that the best chance for older people to retain their sense of identity, continuity, and meaning is to be in their own homes and communities,” says Kane.
A prolific, widely published author, Kane is a professor in the School of Public Health at University of Minnesota, Minneapolis. She also serves on the graduate faculty of the University’s School of Social Work and as a faculty associate for the University’s Center for Biomedical Ethics. Over her distinguished career she has been a visiting lecturer and professor at numerous universities, worked as a social scientist for the Rand Corporation, and conducted multitudes of research projects on long-term care in all settings. An avid researcher, Kane has merged her ongoing interest in values and ethics with her interest in LTSS, conducting several projects to identify ethical issues that arise in all LTSS settings.

Kane believes that LTSS are vital to a good quality of life: they’re about how and where people will live when they need sustained, safe, and compassionate healthcare. “I want Generations readers to realize the importance—from a consumer perspective—of having flexible, individualized, affordable HCBS. I would urge people to think more than twice before deciding that someone needs a nursing home, thinking instead of what services are needed and how to pull them together. I hope the examples in this journal illustrate that HCBS are really possible for most people. But I also hope it will show that though many good minds in gerontology have been working on this topic for decades, the old problems still exist: lack of coordination, high costs, quality concerns.”

Though she acknowledges what has been done, Kane sees the benefit in “looking back at our history to see how policy and programs evolved, and realizing that when our programs were developed, they were framed by various assumptions”—assumptions that might have outlived their relevance, with new ones now replacing them.

That said, Kane sees a landscape of challenges ahead: the creation and proper remuneration of the caregiver labor force; how to achieve a balanced integration of technology and “hands-on” patient care; how to deal with the increasing numbers of elders (although she says this demographic might help “normalize” LTSS); how to support elders’ affordable access to LTSS over time, given our unstable economy; how to educate elders and their families about available options for LTSS, with timely, effective access; and the perennial challenge of developing “a constituency group of seniors for HCBS.”

Kane admits that the research base for learning the most effective way to organize and deliver HCBS is weak, with most of the attention focused on appropriate levels of placement and whether HCBS are a cost-effective alternative to nursing homes. Her HCBS “wish list” would include a targeted research agenda that speaks to practice.

“If and when—and I hope it is when—HCBS become the model approach, and institutional care the rare alternative, we will have quality problems. We must guard against them with sound system design, and find ways to fix them without reinventing an institution.”

—Alison Hood

The research base for learning how to organize and deliver HCBS is weak: Kane’s ‘wish list’ includes a targeted research agenda that speaks to practice.
Thirty Years of Home- and Community-Based Services: Getting Closer and Closer to Home

We are progressing to where the norm for long-term services and supports is that they are based at home and in the community—with nursing homes being the rare-choice alternative.

In 1982, the first Medicaid Home- and Community-Based Services (HCBS) waiver began operating in Oregon, making 2012 the thirtieth anniversary of HCBS—an occasion to reflect on how far we have come and how far we have to go in making services available for older people with substantial disabilities or chronic disease.

Like the old folk myth about falsely lulled frogs, slowly (and unknowingly) cooking to death in water gradually brought to boil; we in the field of aging may be unable to fully appreciate thirty years of change because of its incremental nature. Or, conversely, we may selectively use information and anecdotes to exaggerate current opportunities for elders seeking long-term support in the community. I suspect both phenomena are occurring. To help us determine what celebrations are merited—and what work remains to be done—this issue of Generations examines the scope of a thirty-year history, and the reality of present-day challenges.

Long-Term Care in the Immediate Pre- and Post-Medicare Era

My career in social work began in 1965, a banner “Great Society” year when Medicare, Medicaid, the Older Americans Act, and the Community Mental Health Center Act were initiated. In that halcyon time, government seemed willing to invest in improving the social fabric for all citizens. And by 1965, nursing homes were already the predominant form of publicly funded long-term care in the country; in the preceding decade, public money had been used to encourage their construction. New payment sources and new post-Medicare regulations finished the job of forcing out of business the less medically oriented or less sophisticated programs, known as “Mom and Pop” operations.

Certainly, in the decades before and after 1965, older people and their families tried to provide for what we now call long-term supportive services (LTSS) at home, but few data were available about how they managed to leverage unpaid help of family members and private-pay supplementation—usually from self-employed helpers and private duty “nurses.” (In 2012, there is still little information about private LTSS arrangements.) When older people needed significant, labor-intensive personal care beyond what family members could provide, especially when they lacked family assistance or struggled
with advanced Alzheimer's Disease and other cognitive impairments, they entered nursing homes. Sometimes elders were supported initially with time-limited funding from the new Medicare program for post-hospital rehabilitation, followed by a “spending down” of their private resources, which resulted in their becoming part of the “medically needy” group financed by the new Medicaid benefit. About a half of nursing home costs were accounted for by Medicaid, and most of the remaining half by private payment, with a sliver for Medicare. Only the very wealthy could afford to purchase HCBS with private resources.

Yet as early as the mid 1970s, the bloom was off the rose for the nursing home industry: few older people wanted to enter nursing homes (however exemplary), and many families felt wretched about needing such so-called placement.

Two forces ushered in the search for alternatives to nursing homes—a Holy Grail quest of the ’70s and ’80s. First, nursing home quality was often notoriously poor—both in the provision of healthcare and the amenities of everyday life. Scandals abounded in the sector relating to dubious real estate deals, suspect financial transactions, and neglectful care and conditions discovered in so-called Medicaid mills. While philanthropic and religious organizations raised money for state-of-the-art nursing homes and the business sector created nursing home “chains,” their quality was challenged. Muckraking books appeared: Old Age: the Last Segregation (Townsend and Nader, 1971); Tender Loving Greed (Mendelson, 1974); Too Old, Too Sick, Too Bad (Moss and Halaman-daris, 1977), which grew out of Senate hearings on quality; and Unloving Care: The Nursing Home Tragedy (Vladeck, 1980).

Even more telling, nursing home care quickly became a drain on state government coffers. Medicaid was supposed to be a “safety net” healthcare program for low-income Americans, but quickly became a large and expensive program for middle-class Americans who had expended their resources in nursing homes. By the mid ’70s, the search for alternatives was on. Richard Ladd, to whom this issue is dedicated, tirelessly pointed out the three major classes of expenditure that drive state budgets: education, correctional systems, and Medicaid expenditures—the bulk of which are LTSS for elders and people with disabilities rather than acute care for the poor.

A Quest for Alternatives
From the 1970s on, advocates railed against an institutional bias in Medicaid, suggesting that for want of small expenditures in the community, people were forced to move to more expensive nursing home care. At that time, demonstration programs were developed to test the contention that HCBS could be a cost-effective alternative to nursing homes under Medicaid. These included (among others) Access, in Rochester, New York; Connecticut Community Care; the Wisconsin Community Options Program; California’s Multipurpose Senior Services Project; and South Carolina Community Long Term Care. Experimental waivers to the Medicaid program (dubbed 1115 waivers because of the statutory clause being waived) funded many of these programs.

During the same period, some newly formed area agencies on aging—notably in Florida, Massachusetts, and Pennsylvania—established statewide networks for socially oriented, “non-medical” in-home services. And there was a major demonstration, conducted under Medicare, which was one of the few research demonstrations that went beyond studying people eligible for Medicaid. In a randomized controlled trial, Medicare beneficiaries were
assigned to new benefits for adult daycare or homemaker services (Weissert, Wan, and Livierios, 1979). These studies generated mixed to disappointing results in making the cost-effectiveness case for HCBS: the unit costs of HCBS might be less than nursing homes, but unless HCBS actually resulted in shrinking the nursing home sector, it was more likely an added cost than a substitute for institutional care. And HCBS were not always cheaper; policy critics realized HCBS needed to be targeted to people at the frail end of the spectrum of cognitive or functional ability for an apt comparison. The term “woodwork effect” became common when describing people who would avoid nursing homes because of their aversive characteristics but might “come out of the woodwork” to use HCBS.

In 1980, after several years of planning, clients were enrolled in the ambitious Long-Term Care Channeling Demonstration, a randomized controlled study in ten states meant to finally answer the question of whether HCBS could be a cost-effective alternative. This massive project helped create a state infrastructure for HCBS. But well before its mixed results were available (Kemper et al., 1988), HCBS waivers came into effect, enabling states to get federal permission to waive various Medicaid requirements to offer HCBS. To be approved, states had to show that their total expenditures under Medicaid for HCBS and nursing homes grew no more than expected without the waiver. Many states promulgated more generous financial eligibility for the waivers so people with incomes 200 percent or 300 percent of poverty level would be eligible, but functional eligibility was required to match the eligibility for Medicaid nursing homes in a state.

Thus, through the ’70s and ’80s, HCBS was not judged on its own merits, but on whether it cut use and costs of institutional services. A by-product of the quest for cost-effective alternatives is that LTSS in the United States have been framed as an issue related to poverty and the safety net for low-income people, and the major social experiments to date have been developed within the Medicaid program. Outside of their function to license health and LTSS providers, the main role of governments (federal or state) has been to pay for services for those who cannot afford them. Most of the available information on LTSS use also is derived from studies of Medicaid clients, despite the fact that many of these had a variety of experiences with LTSS before depleting their resources and becoming eligible for Medicaid.

**HCBS Changes for the ’90s**

By the last decade of the twentieth century, changes were apparent in the way HCBS were envisaged and implemented. Consider the following (sometimes related) developments.

**Younger people need LTSS**

Many younger people, including those with physical or intellectual disabilities incurred at birth or in childhood, and others whose LTSS needs are secondary to injuries or deteriorating diseases with onset in adulthood, began to need LTSS. Steady advocacy by and on behalf of persons with disabilities (punctuated by scandals in state institutions for people with developmental disabilities) began having payoffs. In 1991, the Americans with Disabilities Act (ADA) came into effect, recognizing that people with disabilities had a right to specific accommodations in housing, employment, and public services. By 1993, when a model HCBS program was proposed for the (non-starter) healthcare reforms of the Clinton Administration, multiple populations were incorporated into the plan, including people with serious and persistent mental illness.

**Olmstead has an impact**

In its 1999 Olmstead decision, the Supreme Court held that people should not be required to live in institutions in order to have their medical needs met, unless no more integrated alterna-
tives were possible. Technically, almost everyone in a nursing home and every comparable person in the community could be said to have a disability that qualifies for consideration under the ADA—elders with late-onset blindness, deafness, and mobility or cognitive disabilities may not have initially thought of themselves in that way, but attitudes are slowly changing.

**HCBS programs consolidate services, paradigms shift**

Even before the ADA, many states had begun organizing their HCBS programs to bring services for elders and younger people with disabilities into the same administrative programs. Many states’ departments of aging took on new names to reflect this. The HCBS waivers initiated in 1982 took many forms—some more general and some more specific, but usually large waivers were implemented for persons with mental retardation and developmental disability. Specialized waivers also developed to support LTSS for persons with AIDS and HIV, and traumatic brain injury. As new hybrid departments started forming in many states, differences between goals for HCBS for elders, compared to those for younger people, were highlighted.

The dominant paradigm in services to elders has been to meet unmet needs. The dominant paradigm in disability services is to compensate for disability so people may live as fully as possible. The steadfast rejection of institutions and the insistence on community integration and "normalization" by the disability movement began to have an effect on elders and elder advocates. Plus, some people with disabilities began aging into eligibility for elder services and did not like what they saw. Terms such as “consumer-directed care” and “participant-directed services” became increasingly used in state programs; and the value of consumer choice took on increased salience. Today, the notion of choice has even superseded that of “staying at home,” although the mantra remains.

**Real choices for quality care**

Following Olmstead and President George W. Bush's New Freedom Initiative, the Division of Advocacy and Special Initiatives at the Centers for Medicare & Medicaid Services (CMS) began investing in annual Real Choice System Change (RCSC) Grants to states and other organizations to promote HCBS for persons with disabilities of all ages and all disability types. Beginning in 2001, a decade of such grants has strengthened infrastructures and quality oversight for HCBS.

**Assisted living appears**

The assisted living industry took hold in the late 1980s, rapidly expanding in the 1990s and beyond (Kane and Wilson, 1993). Assisted living, though a widely varying entity both within and across states, is a residential setting aimed largely at elders with LTSS needs. Not formally considered an institution, assisted living residency may offer private occupancy apartments where services can be provided. Depending upon state rules, people with needs equivalent to those individuals in nursing homes may be served in assisted living; and depending on state policies and payment rules, HCBS Medicaid waivers can be used in the service component for elders in group residential settings like assisted living. In 1993, David Barton Smith called assisted living “the killer application”—meaning an innovation that throws all other systems out of whack. Assisted living settings became entrenched entities before regulators and state policy makers could plan for them.

**Yes, Virginia, There Is Progress**

When perceived over thirty years, changes in long-term care for older people may seem slow. Yet broad swaths of data clearly show that more
and more elders are using HCBS than in previous decades. The number of nursing homes is gradually shrinking. According to annual descriptions prepared by Medstat (now Thomson Reuters) analysts of how states spend Medicaid money on LTSS, data show that more and more states are approaching parity in dollars spent on HCBS and dollars spent on nursing homes (see www.hcbs.org/browse.php/nr/source/150/sby/Date/topic). The progress marks substantial gains since earlier studies pioneered by Richard Ladd (Ladd et al., 1995; Kane et al., 1998). The most comparative work is a state scorecard, which rates and ranks not only progress in balancing expenditures, but also aspects of each state’s infrastructure and quality (Reinhard et al., 2011).

Two general strategies can be used to increase reliance on HCBS for elders: preventing entry into nursing homes for long stays (nursing home diversion); and helping elders leave nursing homes (transitions programs). Both strategies are still used, and slowly the message is filtering to professionals, advocates, and potential consumers that nursing homes should not be the automatic choice or only recourse for older adults with LTSS needs. Information systems are a challenge, and it is still likely that those professionals older persons depend upon most for advice—physicians and hospital personnel—are the last to know about opportunities in the community, or to have an incentive to make those referrals.

We have not yet reached the point where the norm for long-term services and supports is at home and in the community, with nursing homes being the rare-choice alternative. But we are getting closer.

**Contents of this Issue of Generations**
The articles herein not only look back over the last three decades, but also look ahead. An initial historical perspective is from authors Terence Ng and Charlene Harrington (page 14). They clarify, as much as current data sources allow, the substantial progress achieved in making HCBS available to elders over the past thirty years.

Articles then cover major programmatic developments since 1982. Many LTSS reforms began as demonstration projects to test different approaches, but ended up either as public policy or a reshaping of how HCBS are offered. Robert Applebaum (page 21) describes the Long-Term Care Channeling Demonstration (he was involved in its design and evaluation in the 1980s). Channeling solidified the centrality of assessment and case management as functions to allocate services, and incidentally spawned a large cadre of leaders who cut their

Assisted living has been called ‘the killer application’—an innovation that throws all other systems out of whack.

LTSS teeth by operating agencies for the channeling demonstration.

Stimulated by successful policies in Europe, where in the 1990s LTSS consumers had been offered cash in lieu of services, federal policy makers began speculating on whether this strategy would work in the United States. Pamela Doty and colleagues describe the Cash and Counseling Demonstration (page 28), a three-state randomized experiment in cashing out Medicaid or Medicaid waiver benefits, and its aftermath.

Jennie Chin Hansen and Maureen Hewitt discuss the PACE program (page 37), an approach to providing LTSS that differs from the HCBS waiver approach. It depends on capitation (i.e., head payment to a provider organization for delivering a full range of services), integrating dollars for acute care and all LTSS (including nursing homes) into one fund to be managed by the organization, and putting the PACE organizations at financial risk for all costs. It also is built around a care model
that includes day health centers, teamwork, and salaried physicians. PACE is the best-known example of integrating care under capitated payments to risk-bearing providers. In all managed care approaches, it becomes crucial that consumer choice on where one lives and how one lives remains, and that care is managed—not lives. The authors argue that when incentives are properly aligned, this result will occur.

Formerly responsible for LTSS programs in Colorado, Dann Milne (page 44) describes the relationship between the evolution of LTSS for elders and the burgeoning disability movement, and lays out accomplishments under the RCSC Grants. Following that, Susan Reinhard, who had been responsible for LTSS programs in New Jersey, describes and offers preliminary results from the current federal demonstration, Money Follows the Person (MFP) (page 52), which encourages states to move long-stay residents from nursing homes to qualifying non-institutional community settings.

Washington State, following closely in the footsteps of its neighbor, Oregon, made enormous strides in HCBS in the 1990s and beyond, developing signature programs and efforts. Charley Reed, formerly responsible for Washington LTSS programs, discusses these states’ accomplishments in pioneering HCBS for elders, the challenges that exist, and what it might take to sustain the programs (page 59).

Reflections on advocacy
In our second section, we offer a bit of “breathing room”—two conversations and an essay on advocacy and HCBS, reflecting the views and expertise of activists who have watched and lived through HCBS developments in their careers and personal lives. Our first conversation is with Bob Kafka, a founder of ADAPT (American Disabled for Accessible Public Transportation), a disability rights advocacy organization; he reflects on commonalities and distinctions relating to disability and aging (page 64).

We next talk with Keren Brown Wilson (page 69), best known for her contributions to developing assisted living in the United States. In this interview she shares her perspectives about arranging HCBS for three of her sisters over many decades. She points to the value, not only of having additional money, but also of having a caring family, while identifying the large holes and system discontinuities that exist regardless of payment source.

Finally, Herb Sanderson, once a director of an area agency on aging and for many years responsible for HCBS for elders and persons with physical disability in Arkansas, discusses advocacy for HCBS for older adults (page 74). He sees some bright spots in the growing interest and capability of state AARP chapters to provide that advocacy for HCBS issues.

A round-up of issues and challenges facing HCBS
The articles in section three deal with LTSS issues and highlight promising LTSS programs. Older adults and their families, and those who provide advice to them (such as hospital discharge planners and case managers), need information about options in real time. The Aging and Disability Resource Centers (ADRC), funded by CMS and AOA under RCSC Grants, have come a long way from the Information and Referral services required under the Older Americans Act. Lisa Alecxih and Carrie Blake-way (page 77) describe the opportunities, challenges, and accomplishments in providing technical assistance to ADRCs in every state.

An ultimate test of HCBS’ capacity is how well the system can respond to consumers in the most difficult circumstances. The next three articles speak to programs for three subgroup populations that offer particular challenges. Debra Cherry describes HCBS for people with moderate and severe Alzheimer’s Disease (page 83), a population that even many advocates do not believe it is generally possible or even desirable to serve largely in the community. Dena Stoner and Marc Gold (page 91)
describe programs for one of the most difficult populations to serve in the community: persons who have both physical disabilities and persistent, severe mental illness or problems with substance abuse. And Jennifer Hayashi and Bruce Leff (page 96) provide an evidence-laden account of the challenges of serving older adults, specifically those with severe or unstable medical conditions, in the community. Their proposed solutions require better integration of primary health care with LTSS and better communication between the acute care and LTSS providers—and remind us how fragmented care still is, even for those living in nursing homes, let alone those living in the community.

Linda Noelker and Richard Browdie turn their attention to family caregivers (page 103), who are part of the LTSS system both as unpaid care providers and as clientele who may benefit from formal care provided to their family members. They describe promising programs—some linked to HCBS waivers in Ohio—and offer a critique on the lack of coherent programs and policies to support families.

Kathy Leitch and colleagues (page 107) provide a description of the flexible, consumer-friendly independent provider attendant program in Washington. All attendants who receive funds from the Medicaid program are unionized, and the union has brought about better wages and benefits, which has increased state costs. This model is likely to expand across the country, as will the union representation. Next, Susan Poor and colleagues (page 112) describe the Beacon Hill Village Movement and the possible role of self-help and mutual support to permit elders, most of whom are not financially eligible for Medicaid, to remain at home. The last two articles in this section bring us to group residential services. Mauro Hernandez (page 118) tackles assisted living, which has been both hailed as a community alternative and criticized as a new institution. He describes disparities in access to assisted living, and explores the question of who gets access to the types of assisted living that offer independence and the amenities of home.

While the quest for HCBS goes on, nursing homes have also changed. Using the example of a twenty-person, two-house nursing home (trademarked a Green House) in suburban Rochester, New York, Robert Jenkens and colleagues argue that a nursing home can also be an HCBS setting, if located in a neighborhood with easy accessibility to the community (page 125).

And...in Conclusion
In this issue’s final piece, Robert Kane and I offer a short article about next steps for HCBS (page 131). As I reflect on our table of contents and the thoughtful articles it contains, the following two points come to mind.

An elderly person who needs LTSS typically needs three components: a place to live that is easily negotiated despite disability, and is conducive to receiving services; labor-intensive personal care and supportive services construed broadly to include routine nursing, medication administration, and equipment provision; and medical and other specialized health services. Unlike most younger people with LTSS needs, people in their eighties and nineties are likely to have intermittent or continuing need for medical oversight. Our systems rarely bring these three components together well.

Finally, at the heart of the HCBS topic are older people trying to live out their lives in circumstances and communities that afford them meaning. Meika Loe (2011) spent three years following thirty seniors, ages 85 and older (at her study’s start), documenting survival strategies, priorities, and decisions. For those “largely invisible” elders, she says, “doing old age is largely about what one has done all along.”

**HCBS can support older people to live their lives in the circumstances and communities they find meaningful.**

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We have come a long way in HCBS over thirty years, but we still have not achieved an optimal infrastructure to help elders maintain continuity of life and spirit when faced with persistent erosions of functional ability, cognitive decline, or dramatic changes in health status. A worthy goal is to allow old age to be about doing what one has done all along.

Rosalie A. Kane is a professor in the School of Public Health at University of Minnesota, Minneapolis.

References


The federal-state Medicaid program plays a critical role in long-term care (LTC) financing for both nursing home and home- and community-based services (HCBS). In 2008, Medicaid paid for 38 percent of the nation’s $195 billion in LTC expenditures (CMS, 2011a). The Medicaid program is facing growing financial pressures to pay for LTC as the total number of elderly participants receiving Medicaid LTC has increased, along with LTC spending (CMS, 2011b).

As Medicaid nursing home costs have increased, social and legal pressures have mounted on state Medicaid programs to rebalance their LTC systems away from providing nursing home care toward HCBS. The main legal support for such rebalancing is the 1999 Olmstead Supreme Court ruling stating that individuals have the right to live in the least restrictive setting, and that forcing individuals who could live at home into nursing homes constitutes discrimination (Carlson and Coffey, 2010). This ruling has spawned more than 130 lawsuits against states for failure to provide adequate HCBS. Over the past thirty years, the federal government and Congress have developed Medicaid-optional programs to pay for HCBS including the 1915(c) waiver program and the Personal Care Services program. In addition, they have encouraged rebalancing through legislative and program initiatives, including the New Freedom Initiative of 2002, the Deficit Reduction Act of 2005, and the Affordable Care Act of 2010.

Medicaid HCBS Programs for Elders
Institutional services have been mandated as Medicaid benefits for elders (and all other populations) along with home healthcare, while other HCBS programs are optional (Kitchener, Ng, and Harrington, 2007a). In addition to home healthcare, the two major optional Medicaid programs that serve elders are HCBS waivers and the state plan Personal Care Services (PCS) benefit. The following section

Elderly participants in Medicaid HCBS waivers, home health, and state plan personal care services grew 53 percent in 2008.

Although states have progressed in rebalancing services for elders and increasing the use of home- and community-based services, the process is slow.
compares the main features of the three Medicaid HCBS programs, emphasizing that they are not direct substitutes for one another, and participants may receive services from one or more HCBS programs.

**HCBS waivers**

Since 1981, states have used the authority under Section 1915(c) of the Social Security Act to request a waiver of certain federal Medicaid requirements (including statewide program coverage) to establish 1915(c) waiver programs. Typical services provided in elderly waivers include case management, modification of the home and vehicles to accommodate mobility issues, and respite, among others. These programs must be targeted to individuals in specific groups, such as elders or the physically disabled, who otherwise qualify to be in an institution or are risk of being placed in an institution. The waiver programs must also be cost-neutral, by demonstrating that each waiver’s participant costs are no greater than per participant institutional costs for a comparable level of care (Harrington, Ng, and Kitchener, 2011).

States can control costs in three ways (Harrington, Ng, and Kitchener, 2011): states can set limits on the number of available participant slots on each waiver; states can set financial eligibility as well as need criteria for waivers and cap spending on services provided; and states may limit waiver programs to certain geographical areas.

States are required to report annual waiver data to the Centers for Medicaid & Medicare Services (CMS) on Form 372 waiver reports. Although some waivers are targeted specifically to elders, many states serve this population in waivers that also serve the disabled. Therefore, the data for elders cannot be separated from that for the disabled in combination waivers, so both elderly and the combination of elderly and disabled waivers are included in this article as elderly waivers.

**Personal Care Services**

Personal Care Services, established under a Medicaid state plan option in 1975, allow individuals to maintain independence in their home and the community (Kitchener, Ng, and Harrington, 2007b). States have considerable discretion in defining PCS, but programs typically involve non-medical assistance with activities of daily living such as bathing and eating. Unlike waivers, the PCS state plan option must be available to all categorically eligible groups, including elders, and states can opt to include the medically needy (those who spend down to the state standard because of medical expenses) (Kitchener, Ng, and Harrington, 2007b). States may also provide PCS through their 1915(c) waiver programs. These services are primarily provided to elders, but because Medicaid data do not include age information, elders cannot be separated out from others with disabilities.

**Home health**

Although Medicaid home health is an allowed service within optional HCBS waivers in many states, it is also a mandatory state benefit for Medicaid participants, including elders. States can vary the amount, scope, and duration of benefits offered as long as these remain sufficient to reasonably achieve their purpose, and are the same for all eligibility groups (Ng, Harrington, and Kitchener, 2010). Generally, home health programs provide services to older people, but aggregate utilization and expenditures data are not available by age group.

**Participation in Medicaid HCBS for Elders and Disabled**

Data from CMS Form 372 waiver reports and the authors’ national surveys of PCS and home health programs show rapid growth in HCBS for elders in terms of the number of programs, participants, and expenditures (Ng, Harrington, and Jhamirah, 2011). The number of HCBS waivers serving elders and disabled grew from sixty-five
in 1999 to eighty-seven in 2008 for all states (and Washington, D.C.), except Arizona and Vermont, which provide services in a managed care environment under 1115 Research and Demonstration waivers. The number of PCS programs increased from twenty-seven to thirty-two states within the same period, with North Dakota, Louisiana, Kansas, Vermont, and New Mexico adding programs over the period. Home health programs were available throughout the United States in the study period.

The number of participants in Medicaid HCBS waivers for elders and disabled, home health, and state plan PCS grew from 1.6 million in 1999 to 2.4 million in 2008—an increase of 53 percent (see Figure 1). This growth was led by a 71 percent increase in state plan PCS participants, while home health grew by 36 percent.

Figure 1 also shows that except for the period between 2005 and 2006, total Medicaid HCBS had an annual increase in the number of elderly and disabled participants. Home health had the largest number of participants (922,000 in 2008) compared to 903,000 in thirty-two state personal care plans, and 598,000 in HCBS waivers in 2008.

In the United States, the total number of elderly and disabled participants receiving Medicaid LTC increased from 3.2 million in 1999 to more than 4 million in 2008, but the number of nursing home residents remained steady at 1.6 million during the same period (CMS, 2011b). Thus the growth is primarily driven by HCBS participants.

Expenditures on Medicaid HCBS
Between 1999 and 2008, the amount spent on Medicaid HCBS for elders and disabled grew by 153 percent, from $8.3 billion in 1999 to $21 billion in 2008 (see Figure 2). Even when taking inflation into account, there was a rise of 96 percent over the period. The annual growth rate slowed markedly in the period from 2006 to 2008; this is probably related to state budgetary constraints. Although the state plan PCS was only available in thirty-two states, it made up the majority of HCBS expenditures. Spending on HCBS waivers for the elderly grew the most (178 percent) over the study period.

Figure 1. Medicaid Elderly Participants in Home- and Community-Based Services for Elders and Disabled, 1999–2008

Source: University of California, San Francisco (UCSF) data collection of CMS Form 372 data for waivers and state surveys of personal care and home health programs for the Kaiser Commission on Medicaid and the Uninsured, 2011.

The largest waiting list was for Texas’ Community Based Alternative waiver: 35,998 persons waited an average of eight months for services in 2010.
Even though nursing home expenditures grew at a slower rate than HCBS, those expenditures make up 70 percent of Medicaid LTC spending, which totaled almost $70 billion in 2008.

**Inter-State Variation of Medicaid HCBS Elderly Waivers**

In 2008, all states (except Arizona and Vermont, which had 1115 waivers) had at least one 1915(c) HCBS waiver that served elders or disabled, and a few states had multiple waivers. Florida led the nation with six disabled waivers, while Rhode Island, Washington, and Montana had four such waivers. With more than 2.4 million elderly participants in Medicaid HCBS nationwide, the average was 7.97 participants per 1,000 people in the United States. The level of participation has varied widely across states. California led the nation with more than fourteen elderly persons in HCBS out of 1,000 Californians, compared with only two elderly persons per 1,000 in Utah and Maryland. Almost $21 billion was spent on Medicaid HCBS for elders in 2008, with California again out in front with more than $4.5 billion spent on such services. New York spent $217 per state resident—the most of any state—while the national average was $69 per population. Utah spent only $10 per state population.

**Rebalancing HCBS Participants and Expenditures**

Despite the steady growth in the number of elders and disabled participants and HCBS expenditures, spending on nursing homes still accounted for a large majority of Medicaid’s expenditure on LTC for elders and disabled. In 2008, 60 percent of elders and disabled on Medicaid long-term care were served in HCBS programs.
(see Figure 3), but only 30 percent of expenditures were for HCBS. The 70 percent of Medicaid LTC dollars spent on nursing homes shows the strong need for more rebalancing between institutional and HCBS for elders and disabled.

**HCBS Waiver Waiting Lists**

One major indicator of unmet need is the number of individuals on waiting lists for Medicaid HCBS waivers. An annual UCSF survey of states has tracked the waiting lists of Medicaid HCBS waivers since 2002 (Ng, Harrington, and Jhamirah, 2011). Figure 4 shows that between 2002 and 2010, persons on elder and disabled waiver waiting lists grew by almost 60 percent to more than 120,000 persons for thirty-three disabled waivers in twenty-two states in 2010. The average time spent on waiting lists to receive services was ten months. The largest waiting list was for the Community Based Alternative waiver in Texas, where 35,998 persons waited an average of eight months for services in 2010. Although the number of HCBS programs, participants, and expenditures for elders and disabled has increased, the unmet needs and demand for HCBS waiver programs are growing.

**Progress Comes with Caveats**

As we approach the thirtieth anniversary of Medicaid HCBS waivers and mark the twelfth anniversary of the landmark Olmstead ruling, states still have much to do to rebalance their Medicaid long-term-care system away from nursing homes and to HCBS. There has been a slow, steady increase in Medicaid HCBS participants and expenditures for elders and disabled in the 1999 to 2008 period, although the growth rate slowed from 2006 to 2008. In contrast, the number of nursing home residents on Medicaid has remained steady from 1999 to 2008, with a 25 percent increase in spending (CMS, 2011b).

In spite of the progress, especially in HCBS participation, 60 percent of elders and disabled in Medicaid LTC use HCBS, but they only make up 30 percent of Medicaid LTC spending, with 70 percent spent on nursing homes. Unmet need for HCBS appears to be large, with states reporting more than 120,000 elders and disabled on waiting lists in 2010, and with average wait times approaching ten months. The varying levels of access and level of services provided through Medicaid HCBS for elders and disabled across states make rebalancing efforts more complex.

With mounting federal and state budget deficits, policy makers face conflicting demands to control Medicaid LTC expenditures, maintain institutional services, and expand HCBS. Although HCBS programs are optional, pressures from Olmstead lawsuits and federal initiatives continue to encourage states toward rebalancing. Various initiatives include the Cash and Counseling demonstrations, Real Choice System...
Change Grants, Money Follows the Person grants, and the Program of All-inclusive Care for the Elderly (PACE) (Summer, 2009).

The 2010 ACA legislation (PL. 11-148) has three important new voluntary provisions for states to expand Medicaid HCBS: a Community First Choice option to encourage more states to provide attendant care services and supports; a state plan amendment to allow waivers to be established as an optional HCBS benefit; and financial incentives to states to rebalance their HCBS program. The first and third provisions offer states enhanced federal matching rates as an incentive to encourage states to increase HCBS participants and expenditures. Although these new provisions are valuable, it is unclear whether states will be willing and able to take advantage of the options, especially for the many states facing serious budget problems (Justice, 2010). Also, the ACA extended the financing for successful HCBS initiatives such as Cash and Counseling and Money Follows the Person grants.

HCBS waiver programs, which are targeted to individuals who would otherwise be in nursing homes, have been required to be cost neutral. A study of HCBS waiver costs for 560,000 disabled elders in 2006 showed cost savings of more than $17,000 per participant annually, with an estimated public savings of almost $11 billion (Harrington, Ng, and Kitchener, 2011).

In spite of these savings, state officials continue to be concerned about potential “woodwork effects,” where individuals “come out of the woodwork” because of the promise of HCBS services, but otherwise wouldn’t have elected to use nursing homes. Although when potential woodwork effects are included in estimates, there are still HCBS waiver savings (Harrington, Ng, and Kitchener, 2011). In spite of the concerns about HCBS cost increases, the need for HCBS programs to substitute for nursing home care is clear.

In an effort to control costs, a number of states have implemented (twelve states) or are planning to implement (eleven states) managed care programs under the Medicaid 1115 waivers to provide HCBS to elders and disabled (Cheek et al., 2012). Under the Medicaid managed care waivers, states can contract with managed care organizations with few federal requirements, so that the impact on access, quality, and costs of long-term care is not clear. Moreover, states are not required to report data on HCBS utilization and expenditures within these managed care programs. This trend may give managed care organizations incentives to reduce access and quality, and may sharply reduce the available data on HCBS and institutional services.

States have much to do to rebalance their Medicaid long-term-care systems away from nursing homes and to HCBS.

Terence Ng, J.D., M.A., is senior research analyst, Department of Social and Behavioral Sciences, Center for Personal Assistance Services, at University of California, San Francisco. Charlene Harrington, Ph.D., is a professor of Social and Behavioral Sciences in the same department.
References


Financial Competency in an Aging Society

Daniel Marson, **Guest Editor**

The Summer 2012 issue of *Generations* will address financial competency in our aging society. Ongoing economic turmoil has impacted the financial future of nearly every population cohort in American society. Older adults, however, are subject to cognitive decline in later life, and now face unprecedented demands to assume responsibility for investment and longevity risk. The issue will focus on three primary areas of interest: the current financial landscape of retirement for elders; a clinical perspective on older adults’ financial capacity; and the legal aspects of financial competency in the aging cohort. Articles will also describe ongoing efforts to educate professionals and to offer protective services to elders at risk for financial incapacity.

**COMING UP IN Summer 2012**

**Generations**
Despite long-standing concerns about quality, by the early 1970s, nursing homes had become the dominant mode of publicly funded long-term-care service provision in the United States. In-home services were barely used in public sector financing for older people. In response to continued criticisms from homecare advocates and policy analysts about the institutional bias of the long-term-care system, more than twenty-five research and demonstration projects were initiated to test the benefits of expanded HCBS (Kemper, Applebaum, and Harrigan, 1987). Common sense would suggest that lower cost homecare would be more cost effective than more expensive institutional care, but most of these studies did not bear that out. The National Long-Term Care Channeling Demonstration was developed in 1980 to provide conclusive data on the topic (Kemper et al., 1988).

All told, the channeling demonstration randomly assigned to the demonstration or comparison groups more than 6,000 older people with disabilities severe enough to qualify for Medicaid nursing homes. Demonstration participants received case management and either the basic or financial control levels of additional in-home services, and control group members received whatever was already available in their communities. The channeling results were meant to dispel any controversies about whether HCBS could be a cost-effective alternative to nursing homes; however, the results did not end the controversy.

Policy makers had hoped that the demonstration would show that an expanded array of case-managed, in-home services would dramatically reduce costs, reduce nursing home use, and improve quality of life for consumers and their caregivers. Although the demonstration reported small improvements in consumer quality of life, nursing home use was not affected, and overall costs were higher for the treatment group (Kemper et al., 1988). Even so, the United States has dramatically expanded the in-home care available to individuals with severe disability, and this has proven to be a good policy decision. This article examines channeling.
The Long-Term Care Channeling Demonstration Defined

The channeling demonstration was able to test, through a rigorous experimental design, the effectiveness of HCBS for nursing home–eligible participants. Channeling projects were conducted in ten states using the following two forms of an HCBS intervention:

✓ **Basic Channeling.** Implemented in specific regions of five states (KY, MD, ME, NJ, TX), Basic Channeling offered case management services plus payment for small amounts of additional “gap-filling” services to test the hypothesis that major barriers to HCBS services for elders with nursing home–level needs are lack of information and assistance to coordinate a plan of services.

✓ **Financial Control Channeling.** Also implemented in specific regions of five states (FL, MA, NY, OH, PA), Financial Control Channeling offered case management, but case managers were empowered to purchase HCBS services (up to a cap not to exceed 60 percent of the average cost of Medicaid nursing home care in the state), testing the hypothesis that provision of additional services under Medicaid would be more likely to stave off nursing home use. Services that could be authorized included personal and homemaker care, home-delivered meals, adult daycare, home health aide, nursing, transportation, non-routine medical supplies, adaptive and assistive equipment, housing assistance, mental health services, and respite care.

evaluation results in the context of twenty-five years of additional experience delivering in-home services.

Lessons from Channeling

The channeling demonstration provided important lessons about the delivery of in-home services and how to conduct large-scale applied evaluation research. Program findings, both on process and impact, have proven useful to local, state, and federal staff working to refine the long-term services and supports (LTSS) delivery system.

**What we learned**

The lessons learned from the demonstration include the following:

• **Despite increasing the amount and type of in-home services provided to channeling participants, there was little reduction in the care provided by family members.** Policy makers had been concerned that families would reduce their care efforts if formal paid services were increased. While family tasks in some instances changed, families and other informal system members remained heavily involved, with little substitution.

• **Channeling resulted in small improvements in participants’ well-being.** There were decreases in unmet needs; increases in the services used; confidence generated with receipt of care; and satisfaction with service arrangements and life quality. The research provided additional experience in measuring important elements of service and life quality, and highlighted the challenges in quantifying such critical concepts.

• **Channeling demonstrated that individuals with severe disability could be served safely at home.** This countered concerns that older individuals with severe disability would be unsafe at home. The demonstration provided evidence indicating that individuals could receive long-term services and supports in a range of settings.

• **Channeling case management agencies developed considerable expertise in the provision of case management.** This was seen both in terms of the assessment, care planning, and monitoring tasks of care man-


management, as well as in the contracting and monitoring practices that were required to work with the array of in-home service providers delivering hands-on care to program participants. Concerns that unsupervised in-home workers would result in a plethora of abuse claims and overall poor quality of care did not prove to be correct.

- **Channeling clearly demonstrated the need for programs’ sites and researchers to collaborate to implement and evaluate a real-world intervention.** With today’s renewed emphasis on evidence-based practice, the channeling legacy of partnership highlights the fact that rigorous research with older people with severe disability can be done, and underscores the importance of agency partners in implementing such an effort.

An added benefit was that the demonstration created a generation of program administrators, policy makers, and researchers that built on the channeling experience to generate new knowledge and experiences, which helped shape today’s HCBS delivery system.

**What we didn’t learn**

To supplement the experimental design, an extensive process analysis component of the study provided insights into how the intervention was implemented, and helpful information to better interpret evaluation results. For example, in many communities, some control group members had access to similar case-managed in-home services, weakening the potential impact of the intervention. Because the process analysis was primarily linked to the impact evaluation, the study was unable to test many critical elements of homecare operations. This was not a failure on the part of the study, as the research was designed to assess the effectiveness of case-managed in-home services. Unfortunately, even though the United States has seen a dramatic increase in HCBS since 1986, subsequent studies have not addressed many of the critical questions about how to best implement such a homecare intervention.

Study analysis produced the following findings:

- Despite spending a considerable effort to target individuals who, but for channeling, would have been in a nursing home, after six months only about 13 percent of the control group used nursing homes and, after one year, 21 percent did so. Although treatment group members recorded fewer days in a nursing home, the differences were not large enough to offset the increased use of in-home services. This meant that over the twelve- to eighteen-month follow-up period, costs were higher for the homecare group. Predicting nursing home placement has provided important fodder for an array of master’s and doctoral dissertations, but our ability to understand the complexity of the nursing home placement decision remains limited.

Demonstration results again reinforced the difficulty in knowing exactly which older people with disability will use nursing home care, and this has contributed to further efforts to refine HCBS eligibility criteria.

- The provision of case-managed HCBS requires numerous program decisions ranging from the optimal case load for each care manager to the intensity and nature of case management activity for the right type and amount of in-home services. The demonstration did not provide empirical data to answer these programmatic questions and neither has subsequent research over the past twenty-five years. Some researchers (Weissert, 1988; Greene, 2005) have argued that the key to cost-effective homecare lies in getting the service dosage right (titration), but this and

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*Would someone adverse to nursing home care because of its negative qualities ‘come out of the woodwork’ to use homecare?*
other refinements have not occurred since the conclusion of the channeling demonstration.

- Case management, or care coordination, has become the core component of HCBS both in the United States and globally. Empirical information about the types of discipline and training required to be an effective care manager was not part of the demonstration, nor has subsequent research addressed this topic. Some states have limited care managers to such licensed professions as nursing and social work, while others have cast a wider professional net. In addition, there is no uniform curriculum or training regimen even though case management has become a national component of the homecare system. Finally, others have raised questions about whether the concept of care management is paternalistic and whether an entirely new model is now needed.

- Critics of inappropriate nursing home use have argued that there are various negative factors associated with placement, such as lower physical and cognitive functioning and lower quality of life. Our ability to define and measure these concepts was limited in the channeling evaluation and remains compromised today. Even the measure of physical functioning, initially established almost fifty years ago, requires refinement (Katz et al., 1963). For example, when measuring the ADL task of dressing, we observed that those who lived with others were sometimes more likely to report needing assistance with this as compared to those who lived alone—even though there appeared to be no differences in actual ability to perform the task. Measurement problems continue to exist across the array of outcomes that homecare has been hypothesized to improve, limiting our ability to assess effectiveness.

- Finally, the channeling demonstration did not clearly test how to efficiently provide case-managed in-home services. For example, is it better to have a small number of in-home providers or a large pool for consumers to choose from? Is adult daycare a better approach than an in-home worker? What is the best way to identify, recruit, and assess those in need of in-home services? How do we assess individuals’ values about the type and amount of assistance that they desire? To this day, little empirical work has been done to improve the efficiency of in-home services, despite the wide expansion and acceptance of in-home services as a core system element.

**Channeling Parsed Through the Lens of the Post-1985 Experience**

Ironically, despite the extent and expense of the National Long-Term Care Channeling Demonstration, the channeling results had a limited impact on social policy. In fact, the Omnibus Reconciliation Act of 1981, which created the opportunity for states to apply for waivers to Medicaid to create HCBS programs, was passed during the first year of the demonstration and five years before evaluation results were released. Had channeling results been available and used, a much more limited waiver program might have been passed. For example, given the pressures on cost, based on the channeling results, the new waiver program might have limited participant access to those going through a nursing home pre-admission screening process as a way to better target homecare services. Instead, the Medicaid waiver, while requiring individuals to meet the state’s nursing home level of care criteria, was open to a wider target population. Using this broader strategy, in 2010, the United States spent more than $36 billion on home- and community-based waiver programs, demonstrating how these services have become a critical component of the system. In 2010, six states spent more Medicaid funds on home- and community-based services than on institutional care, a ratio that was practically unimaginable during the channeling era (Eiken et al., 2011).

In another interesting twist, although channeling and most of the other demonstra-
tions of that period focused on serving older people outside nursing homes, less than one-quarter of waiver funds today are actually allocated to individuals ages 60 and over, with the majority of funds (71 percent) used to serve individuals with developmental disabilities (Eiken et al., 2011). Demonstrations evaluating the expansion of waivers for individuals with developmental disabilities were rare, yet these programs now use the majority of in-home care resources. Today, I believe, along with many other long-term-care analysts, that the expansion of in-home services was good public policy.

Ohio study provides perspective

Data from an eighteen-year longitudinal study conducted in Ohio (Mehdizadeh et al., 2011) can provide perspective for understanding the channeling conclusions twenty-five years later. Although these results represent the experience of only one state, they offer a detailed review of changes in long-term services and supports. Albeit somewhat more slowly than many states, Ohio has made considerable progress in transforming its LTSS system. In 1993, more than nine out of ten older Ohioans receiving Medicaid LTSS did so in an institutional setting. By 2009, that proportion had dropped to 58 percent. The primary reason for the proportional shift was a dramatic increase in two HCBS waiver programs providing in-home services and assisted living. For example, between 1997 and 2009, the state increased its daily waiver utilization rate for older Ohioans from about 14,000 individuals each day to more than 30,000. The critical policy question is: What impact did the homecare expansion have on system costs?

The channeling results would suggest that this wide-scale expansion may have enhanced access to in-home care and could have improved quality of life, but would ultimately increase use and system costs. Policy analysts examining channeling data have consistently used the pejorative term “the woodwork effect” to describe an expected increase in homecare recipients once a new homecare benefit becomes available.

In his 1821 evaluation of almshouses in Massachusetts, Josiah Quincy recommended that indoor relief, rather than outdoor relief, should be the public mode of assistance to meet individual needs (Axinn and Levin, 1975). He reasoned that although care in almshouses is more expensive, most individuals would do everything possible to avoid such care because conditions in almshouses were deplorable, thus making indoor relief less attractive, less likely to be used, and less costly in total expenditures.

Using the same logic as the Quincy evaluation, some policy analysts reason that an individual adverse to nursing home care, because of its negative qualities, would “come out of the woodwork” to use homecare. Although there has been considerable speculation about this

Figure 1. Number of People Ages 60 and Older Residing in Nursing Facilities or Enrolled in a Waiver Program, 1997–2009

![Figure 1. Number of People Ages 60 and Older Residing in Nursing Facilities or Enrolled in a Waiver Program, 1997–2009](image)
potential outcome, little empirical data have been available to address this question.

The Ohio study, which examined total state activity, not the results for a particular time-limited and place-limited experimental group, indicates that the woodwork effect did not occur. Figure 1 (page 25) illustrates long-term care Medicaid participation rates for older people in Ohio from 1997–2009. In 1997, Ohio’s 60-plus Medicaid nursing home use rate was 24.5/1,000 and its homecare rate was 7.3/1,000, for a total 60-plus use rate of 31.8/1,000 population. With the expansion of Medicaid waiver participants ages 60 and older, by 2009 the homecare use rate had increased to 13.9/1,000, and the nursing home use rate had dropped to 18.6/1,000. Despite the large increase in homecare use, the total utilization rate was 32.5/1,000 for a population ages 60 and older, quite similar to the 31.8/1,000 rate in 1997. These data indicate that Ohio was able to change how it delivers LTSS to its increasing older population without a woodwork effect that increased total Medicaid LTSS utilization. Similar transformations happened across the United States, with nursing home occupancy rates dropping despite an ever increasing older population.

In Ohio, nursing homes had shifted some of their business away from long-term care.

The changing landscape of LTSS

The system of LTSS has changed dramatically in the twenty-five years since the completion of the channeling demonstration, and many of these changes have affected the results in the Ohio study. One important influential change was the Medicare hospital prospective-payment reimbursement system, which resulted in a large influx of short-term Medicare nursing home admissions. For example, in 1992 Ohio had just over 30,000 Medicare admissions in a system with 92,000 total beds. By 2007, the number of Medicare admissions had increased to 126,500. Even with a drop to 109,300 in 2009, this means that nursing homes had shifted some of their business away from long-term care.

This data—combined with the expanded Medicaid HCBS waiver programs, including the expansion of new self-directed care options, the development and expansion of the private-pay assisted living and homecare industries, the expansion of other long-term living options, and an overall greater recognition of community-based alternatives—demonstrate that the LTSS landscape is significantly different now than in 1986. I contend that these combined changes created a strong enough push to alter the way we provide care. In the end, the channeling intervention, while a rigorous evaluation and demonstration, was just not powerful enough to impact long-term care in the manner that systemic changes would later accomplish.

Conclusion

Do results indicate that the channeling demonstration was a failure and it is time for us to retire evaluation? As an evaluator unready to retire, my answer is no. What the channeling lesson has taught us is that you have to ask the right question—which is not whether homecare is less costly than nursing home care, but rather, what is the best way to provide LTSS for an aging America? Under this framework, research would focus on making sure that the system is as effective and efficient as is possible.

The emphasis on both evidence-based practice and translational research indicates that now is the time for better evaluation research efforts. The channeling experience does reinforce an age-old challenge: the intervention tested must be strong enough to demonstrate an impact. As noted earlier, this is very difficult to do in real-life experiments, as there are many complicating factors. However, the National Cash and Counseling Demonstrati-
tion, discussed by Doty and colleagues in this issue (see page 28), provides powerful evaluation results, indicating that if the intervention is right, impacts can be achieved. Although figuring out the optimal intervention is not easy, it is indeed possible.

What channeling taught us twenty-five years ago was that the practice, evaluation, and policy communities could come together to conduct a large-scale program evaluation on a challenging topic. And that no evaluation result is ever the last word.

Robert Applebaum, Ph.D., is a professor and director of the Ohio LTC Research Project at Scripps Gerontology Center, Miami University, Oxford, Ohio.

References


How Does Cash and Counseling Affect the Growth of Participant-Directed Services?

Elders benefit from tailoring services and supports to meet their specific needs, and paying known caregivers.

Participant-directed services (PDS) offer public program participants the opportunity to exercise choice and control over the long-term services and supports they need to live as independently as possible at home, rather than in residential care facilities. The PDS service delivery model is often referred to as consumer-directed or self-directed services.

The two basic types of PDS—employer authority and budget authority—are differentiated by the scope of choice and control they offer program participants. Employer authority PDS give program participants the authority to hire, manage, and fire paid workers (home health aides, personal care attendants, homemaker and chore workers, and other helpers) of their choosing, rather than being required to obtain aides through homecare agencies.

Budget authority PDS expand program participants’ range of choice and control by providing a monetary allowance, or budget, that can be used to pay personal assistants and purchase other goods and services for meeting disability-related functional needs. Though the budget authority model is often called “cash and counseling,” that label applies only to the fifteen state Medicaid programs that between 1996 and 2008 received grant funding and technical assistance for implementing programs under the auspices of the Robert Wood Johnson Foundation’s “Cash and Counseling” initiatives.

The sidebar on page 29 relates one woman’s experience with a PDS plan.

Proliferation of PDS

As of November 2011, there were 298 PDS programs in the United States—at least one, and typically two or more, in every state (Sciegaj and Selkow, 2011)—more than double the number identified in 2001 (Doty and Flanagan, 2002). Total nationwide PDS enrollment is about 810,000, up from an estimated 450,000 ten years ago. Another way to measure PDS’ nationwide reach is to note that California’s In-Home Supportive Services Program accounts for 59 percent of self-directing program participants nationally—down from more than 75 percent in 2001. Although employer authority programs and their participants (particularly those in populous states like Massachusetts, Michigan, Missouri, and New York, in addition to California) still outnumber budget authority model
Cash and Counseling in Action

“I like this program because I’m the boss,” said Lillian Brannon, more than two years after signing up for the Arkansas Independent Choices Program (Squillace, 2002), one of the three original state Medicaid experimental cash-and-counseling programs sponsored and evaluated by the Robert Wood Johnson Foundation (RWJF) and the U.S. Department of Health and Human Services (HHS). At age 88, “Ms. Lillie,” as she was known to Arkansas program administrators, had been among the first to enroll when the program began in November 1998. She said she decided to switch from using a personal care agency that provided nurse-supervised aide services to Independent Choices because she wanted the opportunity to “have a say in who comes here and cares for me” (RWJF, 2001).

Through Independent Choices, Ms. Lillie received a monthly cash benefit, which she could spend to employ aides of her choosing and purchase other disability-related goods and services (such as assistive technologies, home modifications, transportation, personal care supplies, and home-delivered meals). Ms. Lillie employed a principal aide for weekdays, a second aide to cover weekends and occasional evenings, and a third aide as backup. A fourth person, who lived in her building, served as her “emergency” helper. Ms. Lillie also paid “gas money” to a friend who would do her grocery shopping and pick up personal care supplies and over-the-counter medications—items that, as a Supplemental Security Income recipient, she could not otherwise afford without the Independent Choices monthly stipend.

Ms. Lillie managed her budget via a financial management service (FMS), which program participants refer to as their “bookkeeper.” In Independent Choices and other PDS, the FMS serves as a payroll agent to assure that employment of participant-directed homecare workers complies with applicable federal and state tax, labor, and immigration laws. Though the FMS performs all or most financial transactions, some programs allow participants the convenience of accessing cash to make purchases directly.

Independent Choices provides counselors (often called consultants) who ensure program participants understand the program’s purchasing rules. Upon request, counselors may also give advice on how to recruit, supervise, and, if necessary, dismiss homecare workers. Counselors ensure program participants develop the “participant-centered plan” Medicaid requires whether or not the home- and community-based services (HCBS) will be participant-directed. In budget authority PDS programs, program participants—not professional care managers—write their own plans. The counselors are coaches, encouraging participants to identify personal goals and priorities, and to be creative in identifying necessary goods and services and care providers to best meet individual needs without going over budget or breaking program rules. Counselors also verify that participants have evaluated their risks, and have an emergency back-up plan to address those risks (such as how to get help if aides call in sick or do not show up).
programs, one or more budget authority pro-
grams now exist in all but six states.

Much of this growth can be credited to
widespread dissemination of positive evaluation
of PDS outcomes based on the Cash and Coun-
seling Demonstration and Evaluation (CCDE) in
which three states (Arkansas, Florida, and New
Jersey) participated. Its findings (Benjamin and
Fennell, 2007) were especially compelling
because the CCDE employed a scientifically
rigorous design in which demonstration partici-
pants were randomly assigned to “treatment”
and “control” groups whereby treatment group
members received cash allowances and control
group members received only agency-delivered
aide services or other services authorized by
professional care managers.

The CCDE's strongest positive findings,
shown after eight to nine months, were those
in which treatment group members noted
improved access to paid services and fewer
reported unmet needs for functional assistance.
Treatment group participants and their primary
family caregivers reported increased satisfaction
with the quality of services and quality of life. In
addition, family caregivers reported reduced
stress. Research on other PDS programs has
corroborated the CCDE findings related to
higher satisfaction with quality of care (Doty,
Kasper, and Litvak, 1996; Benjamin, Matthias,
and Franke, 2000; Wiener, Anderson, and
Khatutsky, 2007).

The CCDE budgets were designed to be cost
neutral because they were based on what
formal service providers would be paid if they
delivered services assessed as needed. The
evaluation found, however, that total Medicaid
costs were greater—in some states, for some
groups, in some years—for treatment compared
to control group members.

Subgroup analyses found that for elders,
there were no statistically significant differences
in total Medicaid costs, except in Arkansas in the
first years. This was explained by control group
members, whose personal care services had to
be agency-delivered, receiving fewer—some-

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**Cash and Counseling Initiatives Yield Rich Information**

Readers may wish to explore further the rich case study and process-evaluation evidence from Cash and Counseling initiatives. Qualitative studies complement the comparative CCDE treatment-control group findings, for which Randall Brown of Mathematica Policy Research received Academy Health's 2009 Health Services Research Impact Award.

The RWJF- and HHS–sponsored Cash and Counseling initiatives did not invent PDS. Prototypical cash-benefit programs date back to the period just after World War II, when the Veteran’s Aid and Attendance Program and public and philanthropic programs provided small cash stipends allowing respirator-dependent polio survivors to leave the hospital and receive family and paid attendant care at home.

California’s In-Home Supportive Services program, the largest “employer authority” PDS program, began in the early 1970s (Shapiro, 1993). Cash and counseling did, however, modernize previous approaches to PDS, with specific improvements that added up to a new model. Moreover, the CCDE’s research findings debunked the stereotype that PDS appealed primarily to younger adults with disabilities and was of little benefit to, or even “inappropriate” for, people ages 65 and older.

For more information, visit the National Resource Center for Participant-Directed Services website, www.bc.edu/schools/gssw/nrcpds/cash_and_counseling.html.
times far fewer—authorized aide hours, whereas treatment group members spent most of their allowances on services to meet their assessed level of need. Under these circumstances, providing a participant-directed budget cost Medicaid more in the short run.

By the same token, greater service delivery reliability also made participant-directed budgets more effective in meeting functional assistance needs and, as a result, in preventing and postponing nursing home use. For example, in Arkansas, in the first year of the CCDE, elderly control group participants received only 75 percent of authorized personal care services and total Medicaid costs were 17 percent higher, despite some offsets from reduced nursing home use. In the second year, however, total Medicaid costs for elderly treatment group members were only 4.7 percent higher (not statistically significant) and savings from reduced nursing home use offset 75 percent of the costs attributed to the treatment group’s greater access to personal aide services (Dale and Brown, 2007).

A separate report, a third-year follow-up of Arkansas Independent Choices treatment-control costs, found nursing home savings fully offset increased spending on HCBS (Dale and Brown, 2006) among the 70 percent of treatment group participants (mostly elders) who had used agency-delivered personal care services prior to the CCDE. Subsequent studies by Arkansas officials found reduced nursing home use and other cost offsets balancing out increased HCBS access over the longer term (Doty, Mahoney, and Sciegaj, 2010).

Cash and Counseling Brought Innovations to PDS
The remainder of this article highlights particularly innovative aspects of the cash and counseling model, as pioneered in the CCDE, that have spurred PDS growth by making PDS attractive to older people with disabilities. These features, along with research findings on positive outcomes, also have persuaded public program officials and advocates for elders that it is safe to allow older people to access PDS alternatives to professionally arranged and managed services.

Exercising “budget authority”
Disability rights activists had advocated for years in favor of a cash benefit allowing Medicaid or other public program participants to pay home-care workers directly, reinforcing the program participant’s role as employer. A cash benefit option was included in the Clinton Administration’s health reform proposals for expanded HCBS. The CCDE originally intended to test it, but did not because of concerns about misappropriation of cash provided as a check in the mail or a direct deposit to a program participant’s bank account. Beneficiaries might spend their payments on basic living expenses, luxury items, or vices rather than on goods and services to meet disability-related needs (or third parties could steal the funds). Financial accountability would be difficult to enforce; at best, misuse could be detected after the fact when it might be too late to prevent adverse consequences for program participants, and recover funds.

Federal and state officials were more comfortable allowing program participants (especially elders) to make spending decisions if all or most financial transactions were carried out at the participant’s behest by a third party that assured accountability. Moreover, researchers involved in the planning for the CCDE discovered early on that most eligible Medicaid beneficiaries would be more likely to participate in a program offering a cash benefit in lieu of professionally managed services if Medicaid also paid for such a bookkeeping service (Mahoney et al., 2004). Potential participants said they felt well-qualified to hire, fire, and supervise individual aides, but worried about making innocent

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**Total PDS enrollment is about 810,000, up from an estimated 450,000 ten years ago.**
mistakes, such as filling out tax-related forms incorrectly or making arithmetic errors.

**Family caregivers preferred (and paid)**

Research indicates that older people are attracted to PDS primarily because they want to choose their paid helpers and—more so than younger adults—they often prefer those helpers to be family members. The percentages of treatment group participants, ages 65 and older, who employed relatives ranged from 62 percent in Florida to 76 and 78 percent in Arkansas and New Jersey, respectively (Schore, Foster, and Phillips, 2007).

Many early PDS programs that were designed primarily or exclusively for younger adults with disabilities (in response to disability rights advocacy) prohibited paying family caregivers on the grounds that the relationship between program participants and homecare workers should be strictly “employer-employee.” Similarly, some disability activists have insisted on referring to long-term “services” rather than “care” because providers are paid to provide functional assistance; the affection, emotional support, and intimacy the word care connotes is not necessarily expected—or even desired—as part of the job description.

**Mrs. Maddox’s representative used some of her funds to buy her new dentures.**

Research suggests that HCBS users who prefer to maintain firm boundaries between themselves and paid providers will either choose agency-delivered services or elect to employ non-relatives. But, for many chronically disabled elderly people and their family members, care is an essential component of receiving and providing functional assistance, which is why they prefer to pay family, friends, and neighbors, as illustrated by the story of an early enrollee in Independent Choices, Josie Dickey, and her daughter, Brenda, of Fort Smith, Arkansas (RWJF, 2006).

Following a stroke, Josie Dickey went to a nursing home, where she was neglected and contracted pneumonia. After six weeks, Brenda brought her home to live with her. Brenda continued to work full time, even while recovering from breast cancer. Meanwhile, her mother had to cope with high turnover in agency-hired aides—about thirty aides in three years. When Brenda learned about Independent Choices, she quit her $13-an-hour job and became her mother’s paid caregiver for less than half that. “Before this program,” she explained, “I used to worry about Mom all the time. I’d rather it be me than someone else who doesn’t care as much.”

Beyond qualitative case examples, the CCDE quantitative findings on PDS produced statistical evidence that paying family caregivers results in better quality care and reduces family caregivers’ reported feelings of stress, without lessening families’ provision of informal help (Simon-Rusinowitz et al., 2005). Although many states still have prohibitions on paying family caregivers, they now apply primarily to spouses and parents of minor children (Sciegaj and Selkow, 2011). Two of the original CCDE states (New Jersey and Florida) specifically requested permission to experiment with paying spouses, something that the Centers for Medicare & Medicaid (CMS) did not then permit either in state plan personal care programs (as a matter of law) or in HCBS waiver programs (as a matter of agency policy). Other states with employer or budget authority PDS programs (California, Minnesota, Oregon) were emboldened to ask CMS for permission to pay spouses, and CMS decided to exercise its administrative discretion to allow payments in both “1115” and HCBS waiver programs.

In Minnesota’s Consumer-Directed Community Supports program, Violet Hamilton was able to earn enough as her seventy-year-old husband Harold’s paid aide to quit her job at a Frigidaire plant an hour from home so that she could take care of him around-the-clock. Harold’s diabetes was not well controlled and he had frequently been hospitalized. Neither Harold nor his
previous agency-employed homecare aides could recognize when he was in danger of going into insulin shock, but Violet knew the signs and could act to prevent an episode. Before Violet became his paid caregiver, Harold had a heart attack and his doctor gave him two months to live. A year later, he was still alive, still at home, and had not been re-hospitalized for insulin shock.

**With our increasingly diverse older population, flexible long-term-care delivery is all the more necessary.**

A study of California’s In-Home Supportive Services program (Newcomer, Kang, and Doty, 2011) found Hispanic and Asian elderly program participants were more likely than whites or blacks to hire relatives, including spouses, although regardless of ethnicity, program participants tended to employ family members if they were able and available to work. The 2005 Deficit Reduction Act amended Medicaid law to authorize spouses to be paid caregivers, at the state’s option.

**Designated “representatives” help with decision-making**

Disability rights activists, who for many years were the most politically vocal advocates for PDS, emphasize “self” direction. Accordingly, some PDS programs accepted only applicants with fully intact cognition. The CCDE took a more inclusive approach, developing and formalizing the role of a designated “representative” to assist PDS program participants with decision-making or act as surrogate decision-makers for those with dementia or other cognitive impairments. A representative—almost always a family member who is well acquainted with the program participant’s needs and preferences—may not be a paid helper.

The possibility of designating a representative opened participation by older Medicaid beneficiaries in PDS programs far more than would otherwise have occurred. For example, Gregorio Cruz, an eighty-six-year-old participant in Florida’s Consumer Directed Care program, had Alzheimer’s Disease, along with other chronic diseases, and could not have joined the program without a representative.

Mrs. Janice Maddox, age 74, of Pine Bluff, Arkansas, would not necessarily have been excluded from participation in Independent Choices had she not named a representative to assist her, because her disabilities were physical, not cognitive. However, because she did not feel comfortable making her own care arrangements, she chose her eldest daughter Johnetta as her representative. Johnetta, who hired and supervised other family members to provide her mother’s care, said, “She doesn’t get nearly as many allergic reactions or bed sores now, and I think that’s because when it’s your own [you’re] looking after, you pay more attention” (RWJF, 2002).

**Purchasing flexibility appreciated**

Program participants and family caregivers appreciate the flexibility that budget authority PDS programs give them to purchase goods and services other than aide services (Nordstrand et al., 2009). Compared to younger program participants, older participants generally spend a higher percentage of their funds on human assistance and less on assistive technologies and home modifications. Most of their spending beyond aide services tends to be for health and personal care items, such as incontinence pads, that Medicaid does not cover outside of a nursing home. In other cases, a state Medicaid program’s optional benefit coverage falls short. For example, Mrs. Maddox’s representative used some of her funds to buy her new dentures.

A detailed study of Arkansas and New Jersey CCDE program participants’ use of their budgets to purchase goods and services other than help from paid aides found some age, gender, and racial differences that were sizable at baseline had subsequently narrowed. For example, black treatment group members used their budgets to
acquire assistive technologies and home modifications that a much higher percentage of whites already had (Meiners et al., 2004).

The Future of PDS
There have been setbacks. Since 2008, the economic recession and resulting state Medicaid budget crises have resurrected old concerns such as fears of increased fraud and abuse, and higher costs because of the “woodwork” effect of the cash benefit (the argument that more eligible individuals than anticipated would “come out of the woodwork” to access their benefits), or allowing payments to family caregivers. The Arkansas experience refutes that argument: after twelve years, more than one in five eligible individuals are enrolled in the Independent Choices option, but the total number of elder and disabled Arkansans receiving the Medicaid state plan personal care services benefit has not increased.

In 2010, the Affordable Care Act (ACA) directed the HHS Secretary to develop a voluntary, public long-term-care insurance program called Community Living Assistance Services and Supports (CLASS), design elements of which had been inspired by Cash and Counseling (The SCAN Foundation, 2011). Unfortunately, provisions of the CLASS legislation unrelated to PDS (lifetime benefits; no underwriting) posed daunting challenges to developing actuarially sound, affordable premiums. In October 2011, HHS Secretary Kathleen Sebelius wrote to inform Congress that she was suspending CLASS because she “could not see a viable path forward for CLASS implementation at this time.”

Older Americans whose income will disqualify them for Medicaid or other publicly funded homecare coverage may be able to purchase private long-term-care insurance (LTCI) coverage (if they buy it before they need it and while they can still pass underwriting, which one in five applicants cannot). Currently, 12.4 percent of Americans ages 65 and older have private LTCI (Johnson and Park, 2011). Very few private LTCI companies provide cash benefits along the lines of disability insurance; that is, a regular payment that can be spent without documenting allowable disability-related services purchase. However, the evolution of private LTCI coverage over the past decade strongly suggests private insurers have been influenced by innovations in Medicaid such as budget authority PDS.

Many companies now allow beneficiaries to pay for aide services from independent providers. Many will allow payments to certain family members, and may relax formal training and credentialing requirements. In addition, some companies have added an extra benefit in the form of an allowance, up to an annual maximum, for the purchase of assistive technologies, home modifications, and so on that may reduce reliance on aide services and decrease the likelihood of entry into a residential care facility (Tell, 2011).

In 2008, as the replication phase of the Cash and Counseling initiative (implementation in twelve additional states beyond the three that participated in the CCDE) drew to a close, planning began for a National Resource Center for Participant-Directed Services (NRCPDS) at Boston College. Officially launched in 2009, with funding primarily from The Atlantic Philanthropies and RWJF, the NRCPDS seeks to preserve and build on the legacy of cash and counseling by promoting all forms of PDS, not just within Medicaid. The RWJF has recently funded a study of the potential for using the Medicaid 1915(i) state plan HCBS benefit (enacted in the 2005 Deficit Reduction Act and amended in the ACA) as well as the Substance Abuse and Mental Health Services Administration’s mental health block grants and state revenues to finance self-directed mental health recovery programs.

Since the 2006 reauthorization of the Older Americans Act, the Administration on Aging (AOA) has taken a leadership role in modernizing the aging network, including a variety of initiatives to promote culture change from “professional” to “empowerment” approaches to services and supports, and has enlisted the help of the
NRCPDSD. The AOA has also teamed with the Veteran’s Health Administration to create, with technical assistance from the NRCPDSD, a network of veteran-directed services programs in every state—and with them the infrastructure of the financial management service and counseling necessary for further growth. Veteran-directed HCBS are operating in seventeen states, and the 800 participants enrolled include both aging veterans and recently disabled soldiers.

The ACA established Community First Choice (CFC), a Medicaid optional state plan benefit that assures program participants a certain amount of “employer authority” PDS and authorizes states to offer participants budget authority and permission to employ spouses, at the state’s option. States can claim higher federal financial participation (six additional match points) for CFC. The CFC benefit option became effective October 1, 2011. A number of states are considering it (some have consulted with the NRCPDSD), but are awaiting issuance of final federal Medicaid regulations.

The NRCPDSD is also developing organizational capacity to support and grow PDS through a membership structure for states, an association for financial management services entities, and, most important, the creation of a National Participant Network (NPN). The NPN now has about 300 members and is engaged in business planning to become an independent organization offering member services and providing a voice for PDS program participants and their families at state and national levels.

There is reason to think the PDS movement will continue to grow. With our increasingly diverse older population, flexible long-term-care delivery is all the more necessary. Members of the general public, ages 50 and older, and opinion leaders in the long-term-care field agree (Gibson, 2003; Miller, Mor, and Clark, 2008). Participant direction allows individuals of all ages with disabilities and their families to tailor services and supports to their unique needs and preferences.

Pamela Doty, Ph.D., is a senior policy analyst, Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services, Washington, D.C. Kevin J. Mahoney, Ph.D., is director, National Resource Center for Participant-Directed Services, and a professor at the Graduate School of Social Work, Boston College, Chestnut Hill, Mass. Lori Simon-Rusinowitz, M.P.H, Ph.D., is research director, National Resource Center for Participant-Directed Services, and an associate professor of Health Services Administration, University of Maryland, College Park. Mark Sciegaj, Ph.D., M.P.H., is associate professor of Health Policy and Administration, Pennsylvania State University, University Park. Isaac Selkow is research analyst, National Resource Center for Participant-Directed Services, Boston College. Dawn M. Loughlin, Ph.D., is senior research associate, Center on Aging, at University of Maryland.

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The meaning of the term home- and community-based services (HCBS), as used within today’s long-term supports and services (LTSS) lexicon, has evolved: it now refers to such services as being “from the area in which we live” or refers to those services not provided “in an institution.” The PACE (Program of All-inclusive Care for the Elderly) program, which started in 1971, is now identified as “community-based”—an ironic classification as the program’s beginnings at San Francisco’s On Lok (the prototype for PACE) stemmed from a search for available institutional care for frail elders in the community.

In the early 1970s, members of San Francisco Chinatown’s North Beach community were concerned about their vulnerable elders; they wanted to ensure this group would have an accessible, affordable way to maintain dignity in the face of late-life challenges in health, function, memory, and economic capacity or security. On Lok’s initial day health “community-based care” began when its founders, Marie-Louise Ansak, a Swiss-born, Wellesley-educated social worker, and Dr. William Gee, a Chinese-American dentist trained at the University of California, San Francisco, had been hired to help the community determine how to build a local nursing home because elders were having great difficulty getting into nearby nursing homes.

When elders were able to get a bed, it was often dozens of miles away, and staffed by people who, though competent, could not communicate with this community’s monolingual Chinese, Italian, and Filipino frail elders. Fortuitously, Dr. Gee and Marie Louise Ansak met a geriatrician from Oxford, England, who told them that they should instead build a day hospital where elders could come for clinical and social services but then return at night to their own homes. Thus began the new movement in the United States of day health centers.

**PACE in a Nutshell**

PACE is a program for frail people, ages 55 and older, living in the program’s geographic area, who meet the state’s nursing facility level-of-care threshold, and can live safely in the community with the care PACE provides (Bloom et al., 2011; Kane, 2006). It is called Program of All-inclusive Care for the Elderly because it includes all medical care and supports and services the client needs: primary and specialty care; dental, eye, and hearing care; hospitalization; pharmaceuticals; all therapies, including...
physical, occupational, speech, and recreational; medical transportation; social work services; homecare; mental health care; meals; socialization opportunities; and more. The program assumes full financial responsibility to provide clients with the care deemed necessary by the interdisciplinary team.

The interdisciplinary team includes health professionals from different disciplines—primary care physician, clinic and homecare nurses and attendants, therapists, social workers, registered dieticians, even transportation workers. Together with the PACE client, the interdisciplinary team decides on the Plan of Care, and PACE delivers that care, whether the necessary care is inexpensive or costly.

**Figure 1. PACE Integration and Coordination**

**PACE Promotes Health on Many Levels**

It is well established that elders prefer home- and community-based services (HCBS), but one advantage of HCBS is seldom discussed: their positive effects upon elders’ physical and mental health. PACE emphasizes HCBS that allow people to maintain a sense of place and feel the security of belonging, to know that their preferred ways of living are available, and that life’s celebrated events and holidays can be observed and honored.

These core values, which undergird what is now a codified, community-based, and fully capitated Medicare and Medicaid program, come from simple principles—principles not easily maintained, given the structure of today’s incentives. The PACE program values are to:

- Recognize the importance of function and capacity despite vulnerability in health and life;
- Support learning about and working to honor participants’ preferences and goals;
- Provide the most competent and knowledgeable care and service;
- Support and involve the individual and their family;
- Provide care in a coordinated, integrated, timely, and efficient manner—producing the most impact possible with available resources.

The community-based services PACE provides support the dignity and stability of the enrolled person. They are highlighted in the adjacent diagram (see Figure 1 above), which reflects the health, medical, and socially supportive services that surround older adults and their families. These services help elders maintain effective functioning and capacity (which is vital to the larger arena of public health maintenance), and may include providing eyeglasses, dentures, hearing aids, foot care, grab bars for at-home bathrooms, and recreation. The PACE model also allows for flexibility with other needs, such as help with laundry. Altogether, PACE services, which are reimbursed by global payments, are those that help the provider have both flexibility and accountability for the service model.
PACE clients are usually dually eligible, which means PACE receives one payment per member per month from Medicare (because the client is either old or permanently disabled) and from Medicaid (because the client is usually poor). However, PACE is at full financial risk to provide the care.

PACE is designed around an adult day health center with a primary care clinic, daycare, room for physical, occupational, and other therapies, and meeting space for the interdisciplinary team. Clients usually attend the day center several times a month. There they can socialize with peers and be observed by day center and clinic staff who watch for any condition changes.

Though PACE is designed to keep clients in the community and out of nursing homes, if a client reaches a point where they need 24-hour-a-day care, then PACE is responsible to pay for that care in an assisted living or nursing facility, while still maintaining responsibility for the client’s overall medical and healthcare.

**Denver statistics strongly suggest PACE programs save Medicare dollars at the end of life.**

Beginning with the On Lok experience, the PACE program staff learned early that finding supported housing was often a barrier to living in the community. They have tried many solutions, including helping to arrange for live-in attendants for several PACE members sharing an apartment. The state of Pennsylvania, in its PACE program, has consciously worked with PACE and local communities to situate PACE programs and their day centers in subsidized housing programs.

**Where’s the Growth Ceiling for PACE?**

Over the course of the fourteen years since the initial legislation passed under the Balanced Budget Act of 1997, there are now more than eighty PACE programs across twenty-nine states, with nearly 23,000 enrollees. For each program to work smoothly, with one system and one team for all care and services, there have been years of preparation and learning to work collaboratively, to negotiate with team members and external vendors, and to keep the system of care delivery and financing aligned and accountable.

Many providers handle between 150 to 250 enrollees, which begs the question, can the program be even bigger? Various factors impact the size of programs, but some programs have demonstrated the ability to successfully grow beyond the 250-enrollee ceiling previously established.

**Scaling the Program: PACE at InnovAge in Colorado**

One of this article’s authors, Maureen Hewitt, CEO of InnovAge Greater Colorado PACE (IGCP) in Denver, operates one of the largest PACE programs in the country. Here we share how a much larger enrollee base can be feasible with some changes to the existing structure, changes that reduce regulatory or operational barriers to growth. Growth possibilities are outlined in the context of the new environment under the 2010 Patient Protection and Affordable Care Act (ACA).

Established in 1991, IGCP serves about 10 percent of the national PACE census. Like all PACE programs, IGCP manages these clinically complex and high-risk clients (more than 50 percent have been diagnosed with some form of dementia) with an interdisciplinary team.

InnovAge finds that the biggest challenge to scaling PACE to care for a larger population, like IGCP’s, is PACE’s payment structure and federal regulations.

First, there are significant regulatory obstacles at both the state and federal levels that hinder the program’s ability to grow effectively and efficiently. The elimination of cumbersome rules would allow PACE programs to scale up to serve a significant percentage of the estimated 9.2 million
dually eligible Medicare-Medicaid clients. These barriers inhibit the programs’ flexibility, and do not enhance quality of care. Some suggestions to overcome these barriers are the following:

- Allowing for flexibility in settings where PACE services are provided;
- Allowing flexibility in the composition of the interdisciplinary team in response to each participant’s needs;
- Creating a permanent waiver to allow advanced practice nurses to conduct assessments;
- Creating a permanent waiver to allow the use of community-based physicians;
- Eliminating some staff’s one-year experience requirement working with frail elderly;
- Allowing PACE organizations to enroll nursing home clients to transition them to community settings;
- Providing insurance to cover expenditures beyond revenues for new PACE programs; and,
- Expediting state and federal PACE application processes, which can take years.

A second obstacle to PACE growth is the unpredictability of federal and state capitation payments. One solution would be for the Centers for Medicare & Medicaid Services (CMS) to stabilize federal Medicare PACE payments and pertinent regulations to acknowledge the costs at end of life and the nature of PACE compared to Medicare Advantage (MA) plans. Currently, PACE rates are tied to MA payments, which are paid to insurance companies.

These MA plans charge premiums and co-pays to beneficiaries. When MA payments are decreased, the plans can adjust their premiums, their co-pays, and their benefit package to provide less costly care and services to clients, while PACE programs, whose benefits are prescribed in federal regulations, cannot. There should be a rate methodology protecting PACE programs from these variations.

Additionally, PACE programs, similar to MA plans, are paid based on diagnosis codes. This does not necessarily predict or account for the extreme variation of end-of-life acute-care costs.

An analysis of the Total Medicare Reimbursements per Decedent, by Interval Before Death (Dartmouth Atlas of Health Care, 2003–2007), for the Denver area indicated that claims for Medicare beneficiaries are more than 26 percent more expensive than PACE programs in last two years of life, and more than 65 percent more expensive in the last six months of life. Because life expectancy for a PACE participant in the IGCP PACE program is approximately thirty months, this strongly suggests that PACE programs save Medicare dollars at the end of life.

Another payment issue is that Medicaid rates vary substantially across states (even within states), ranging from almost $5,000 per person per month to less than $2,000. This stems from states using different methods to determine rates and differing definitions of “actuarially similar” populations, which include nursing home clients, home- and community-based waiver clients, or a blend of both. Medicaid programs should allow for an age-adjusted rate structure, to acknowledge the increasing risk of nursing home placement as elders age.

PACE programs should be standardized across states and regions; currently states apply PACE regulations with varying levels of guidance, or no guidance, from CMS. As a consequence, the way states interpret and apply regulations varies considerably. Multi-state providers are required to anticipate variances and adjust programs in each state. As state staffs turn over, the lack of federal guidance creates variations from state to state over time. And, CMS regions often apply PACE regulations differently from region to region, plus surveys are not standardized.

It is advisable to partner with other PACE providers who have established political support.
PACE programs are expensive to start—neither Medicare nor Medicaid rate methodologies consider capital expansion or administrative overhead. Cost reporting could help pay for expansions to include some funding for bricks and mortar, and for operating losses, as PACE programs do not usually reach a break-even point for at least a year or more. Because of the financial risk providers assume when starting a PACE program, a stop-loss policy or a cash reserve is necessary. A cash reserve can be less expensive than carrying a policy to cover losses or catastrophic events. For instance, IGCP serves about 2,200 participants in New Mexico and Colorado; and the cash reserve costs less than the annual premium for this type of reinsurance coverage.

PACE regulations require participants to meet the state’s “nursing home level of care” criteria. However, the definition of nursing home level of care should be standardized because as it now stands, many states define it differently. For example, dementia is well documented in peer-reviewed literature as increasing the risk of nursing home placement, but in California, a diagnosis of dementia alone does not necessarily qualify someone for nursing home level of care.

PACE should be promoted as an optional state plan benefit in all states. This would be consistent with the states’ push toward Medicaid managed care, and would focus on controlling costs for dually eligible beneficiaries.

Alternatively, CMS could allow a two-way agreement between CMS and the PACE provider to enroll Medicare-only participants in states that do not authorize PACE as an optional Medicaid State Plan benefit. This could encourage private pay, Veterans Administration, and long-term-care insurance participants to enroll in PACE.
The CMS could support the elimination of unnecessary overlapping requirements. State and local regulatory requirements are often redundant (home health or adult day licensure). The CMS should offer guidance on streamlining or eliminating these duplicative requirements because some are in conflict with PACE regulations.

There are also duplicative reporting requirements to various entities within CMS and the states; these should be coordinated or eliminated.

Most importantly, CMS could eliminate barriers to rapid enrollment. Right now, a client can be enrolled in a nursing home in a day or two, whereas PACE enrollment often takes months. A similar two-day enrollment timeframe should be allowed and facilitated for PACE, including allowing mid-month enrollment and pro-rated payment for Medicare and Medicaid. This should be standardized across all states. Caps on PACE census imposed by states on PACE programs must be eliminated to allow for robust growth.

A new CMS regulation will require that PACE programs (as with MA plans) submit encounter data. MA plans pay claims using procedure codes: PACE programs are providers of care, not just insurance payers, and will be required to establish an internal “superbill” solely to report this information to CMS. This includes pricing services for which CMS does not pay under Medicare for no other purpose than government reporting. This requirement should be limited to aggregate reporting for PACE programs, not client-level reporting.

Another problem for PACE is a lack of supporting data. While there is a substantial body of data on PACE quality, satisfaction, and improved health, there is little published data (and sometimes conflicting data) demonstrating its cost effectiveness, particularly for Medicaid program expenditures. An analysis of Medicaid cost effectiveness should be conducted comparing PACE participants to similar clinically complex clients, not just comparing PACE participants to Medicaid clients older than fifty-five.

InnovAge Greater Colorado, along with other PACE programs in the United States, has focused on expanding PACE, because of its passion for the program, commitment to the mission, and belief that this type of medical home for elders works both clinically and financially.

On average, PACE programs serve about 250 participants, and are either small nonprofit, mission-based programs, or hospital-based programs in which PACE is not a core business. For IGCP, the volume of participants served, along with strong interdisciplinary teams and physicians, were at the core of its mission, and allowed expansion.

**PACE recipe for expansion**

In order to expand PACE programs one needs a strong vision and passion; strong leadership and competency; leadership, staff, and governing board commitment to growth; and commitment to excellent quality and outcomes. It is important to document success and continuously refine what can improve.

It is also important to develop financial and business acumen and look for ways to improve the balance sheet while improving outcomes for clients. PACE programs should develop funding for expansion, or gain financial support from individual donors or corporations who support the mission. The IGCP built its cash reserve as the census increased. This positioned the organization for tax-exempt bonds, and a Fitch rating of BBB—investment grade.

The IGCP also branded its product line, internally and externally; it defines the program. PACE organizations should consider partnering with other organizations with similar values and programs.

Politically, at state and national levels, having an experienced team is crucial. It is advisable to partner with other PACE providers who have established political support for PACE.

The ACA has set up a perfect platform to expand a program like PACE. The ACA required the Secretary of Health and Human
Services to establish a Federal Coordinated Health Care Office (FCHCO) within CMS to provide federal coverage and payment coordination for dual eligible beneficiaries. It also emphasized that Congress should address long-term-care services and supports in a comprehensive way that guarantees elderly and disabled individuals the care they need, in the community as well as in institutions.

These goals align perfectly with PACE and address issues of the disproportionate cost of dual eligibles, and the extraordinary demands of the baby boomer generation for long-term care on their terms, in their communities. This is a time when the PACE program can make a significant difference in the architecture of care for the future.

So What Does It All Mean?

Providing care, a system of quality, and affordable services to frail elders, is now, and will be, a compelling need in society. PACE, in its inception as a program to serve one community’s needs, was not designed to be the solution to the care of frail elders in the community. However, as noted, it is one solution that not only has demonstrated that providing community-based services assists the population who will be needing the services, but acts as a benchmark of what life can look like when incentives in care, financing, coordination, and outcome are aligned to help one remain in community.

In our desire to advance evidence- and quality-based care, we need to remember that metrics in this stage of life and need must include quality of living, personhood, and affordability. Sometimes the need is for a pair of eyeglasses, for the ability to hear, for teeth that can chew food, and for belonging—all of which may mitigate depression, malnutrition, falls, and hospital re-admissions, all measures of performance. It’s the former cluster of factors that are part of framing a different set of community-based services. We should never get too enamored with a concept without asking ourselves what purpose it serves.

Jennie Chin Hansen, R.N., M.S., F.A.A.N., is CEO of the American Geriatrics Society in New York City, and immediate past president of AARP. In 2005, Hansen transitioned after nearly twenty-five years with San Francisco’s On Lok, Inc. In 1997, the On Lok prototype became the federal Program of All-inclusive Care for the Elderly (PACE). Maureen Hewitt, M.S.A., is president and CEO of InnovAge (formerly Total Community Options), Denver, Colorado.

References


After years of activism and strong lobbying by advocates for persons with disabilities, Congress passed the Americans with Disabilities Act (ADA), which President George H. Bush signed into law on July 26, 1990. The ADA mandates the removal of barriers by government and private businesses that deny individuals with disabilities equal opportunity and access to employment, public accommodations, government services, public transportation, and telecommunications. It is revolutionary legislation designed to protect the civil rights of people with physical and mental disabilities, focusing on the concepts of disability, accessibility, and employing its predecessor legislation—the 1964 Civil Rights Act and the 1973 Rehabilitation Act. The transformation wrought by the ADA has benefitted consumers of long-term services and supports (LTSS) of all ages, including elders and people with disabilities.

**The Fruits of Advocacy**

The ADA and its predecessor, the Rehabilitation Act of 1973, were fruits of the disability rights movement, which took impetus and energy from the African American civil rights and women’s rights movements of the 1960s. The disability rights movement aims to secure equal rights and equal opportunities for people denied equality, independence, autonomy, and full access to society. The specific goals are accessibility and safety in transportation, architecture, and the physical environment; equal opportunity in independent living, employment, education, and housing; and freedom from abuse and neglect.

**The Independent Living Movement**

The Independent Living Movement, a key element of the broader disability rights movement, turns on the basic precept that people with even the most severe disabilities should have the same choices that every citizen has to live independently in the community. A major goal of this movement is the right to live independently, using paid personal assistance services if necessary, instead of being institutionalized; it advocates for the removal of all barriers—in public attitudes, transportation, and architecture—

The ADA and Olmstead have benefitted all consumers of long-term services and supports.
The ADA in Brief

The ADA mandate is to protect individuals who have a physical or mental impairment that substantially limits one or more major life activities, who have a record of such impairments, or who may be regarded by others as having such impairments. (The ADA covers all residents in a nursing home, regardless of age.)

The ADA consists of the following five parts:

1. **Title I**, which prohibits discrimination in employment;
2. **Title II**, which prohibits discrimination in programs, services, or activities of public entities (state or local governments), including public transportation;
3. **Title III**, which requires that private businesses that are places of public accommodation allow individuals with disabilities to participate equally in the goods or services they provide, and that new construction must be accessible to individuals with disabilities;
4. **Title IV**, which requires telecommunications companies to make relay services available for people with hearing and speech impairments; and
5. **Title V**, which covers technical legal provisions.

The Triumph of Title II

The ADA defines reasonable accommodations and readily achievable modifications, but over time, Title II has played a major role in transforming the long-term-care system. The Justice Department regulations implementing the ADA’s Title II require a public entity to administer programs in the most integrated setting appropriate to the needs of qualified individuals with disabilities (Code of Federal Regulations, 2010). Under Title II, the ADA prescribes that state and local governments must reasonably modify their policies, practices, and procedures to avoid discrimination. If a government can demonstrate that a modification would fundamentally alter the nature of its service, it is not required to make that modification. A self-evaluation by a government that is used to identify and correct policies and practices inconsistent with Title II can be used as evidence of that government’s good faith effort to comply with Title II requirements.

that interfere with full community living.

A critical aspect of the independent living philosophy is the reframing of how we understand disability—from a medical model to a social (or independent living) model. The medical model seeks to use a medical cure or healing to normalize a person’s condition. The medical model may perceive people with disabilities as lacking and disempowered. For a long time, this model was associated with isolation and segregation. In the 1980s, a social model began to identify societal exclusion, negative attitudes, and system barriers as contributing to disabling people.

Although advocates in aging and of independent living have numerous common areas of interest, the issue of medical versus social model has further unified both groups. Both desire access to independence, dignity, and choice—and their joint activism has moved the system forward.

States step up to HCBS

During the 1990s, states began to build on the initial Medicaid Home- and Community-Based Services (HCBS) waiver program offerings and broaden their long-term-care system capabilities. State administrators soon realized that merely offering an alternative to nursing homes and ICF-MRs (Intermediate Care Facility for
the Mentally Retarded) was insufficient to overcome the historically grounded, institutional bias in the long-term-care system. Using progressive states such as Oregon, Washington, Vermont, and Colorado as models, states began to develop infrastructure to better provide broader choices in community living and quality services. They consolidated long term care programs and budgets, made comprehensive client assessments, used single entry point systems for long-term care access and choice, expanded community-based care services (including assisted living), and strengthened quality management based on information systems.

The Health Care Financing Administration (HCFA) supported this movement toward independent living in its series of reports, Promising Practices in HCBS (Thomson Reuters, 2002–2012), and its support of annual information-sharing conferences. During this time, more than a dozen states participated in the Robert Wood Johnson Foundation–funded Medicare–Medicaid Integration Project to blend acute and long-term care services for dually eligible individuals. Results of this effort include the Minnesota Senior Health Options program and the Texas Star Plus program. Many of these programs’ practices have gained widespread use, including consolidated administrative structures, global budgeting, automated client assessments, single entry (access) points, and improved quality-management systems.

In 1996, the median percentage spent on HCBS by all states for all disability groups was 20.7 percent of their total long-term-care budgets. The top five states were Oregon, Vermont, New Mexico, Wyoming, and Colorado. By 2001, the median percentage spent on HCBS was 29.1 percent, with New Mexico, Vermont, Alaska, Wyoming, Colorado, Washington, Oregon, and Minnesota leading the list (Gregory and Gibson, 2002).

The Olmstead Decision and HCBS

The game-changer for the proportional increase in HCBS expenditures was the 1999 United States Supreme Court decision in Olmstead v. L.C and E.W. Two women in Georgia with developmental disabilities, who were diagnosed with mental illness and being treated in the Georgia Regional Hospital psychiatric unit, sued the Georgia Commissioner for Human Resources (Tommy Olmstead) to be able to be served in a community setting with appropriate support. The state of Georgia’s treatment professionals had already determined it was appropriate to place them in the community. The federal district court concluded that unnecessary institutional segregation constitutes discrimination per se, which cannot be justified by a lack of funding, and ordered their placement in appropriate HCBS programs. Using the ADA’s integration mandate, the Supreme Court upheld the district court and ruled that, under Title II of the ADA, unnecessary institutionalization was discriminatory, in violation of the ADA, and that these women had the right to receive care in the most integrated setting appropriate to their needs.

The Supreme Court stated: “Unjustified placement or retention of persons in institutions severely limits their exposure to the outside community, and therefore constitutes a form of discrimination prohibited by Title II. Institutional placement of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life, and institutional confinement severely diminishes individuals’ every-

People with even the most severe disabilities should have the choice to live independently in the community.
day life activities” (The Su-
preme Court, 1999).

The ruling clarified that the
ADA applies to government
and to the use of public funds
and therefore applies to
publicly funded Medicaid
services for people with
disabilities. The Olmstead
decision confirmed that states
must ensure that Medicaid
clients do not experience
discrimination by being
institutionalized when they
could be served in a more
integrated (community)
setting (Ng, Wong, and
Harrington, 2011).

The Supreme Court pro-
vided guidance about how
states could ensure compliance
with the ADA, indicating that
they should make “reasonable
accommodations” to their
long-term-care systems, but
were not required to make
“fundamental alterations.” The
Court also indicated that
compliance might be demon-
strated by “comprehensive,
effectively working plans,” a
specific version of self-evalua-
tion, to reduce institutionaliza-
tion and increase community-
based services, and by ensuring
that HCBS waiting lists move
at a “reasonable pace” (The
Supreme Court, 1999). These
plans became familiarly known
as Olmstead Plans.

Olmstead Plans
Under Medicaid
Medicaid is the central player
in states’ responses to the
Olmstead decision because it is
the major source of public
funding for LTSS. In the words
of The Kaiser Family Founda-
decision is not a case based on
Medicaid law. Rather, Olmstead
established that State Medicaid
programs must operate in ways
that comply with the ADA.”
Medicaid law requires states to
provide institutional nursing
home services to eligible
individuals as a mandatory
benefit, but does not require
community-based services to
be offered—an often-noted
institutional bias in the Medi-
caid program.

In the community, states
offer home health (a mandatory
benefit); other HCBS services
are optional, such as personal
care, rehabilita-
tion services,
physical therapy,
occupational
therapy, and
transportation
services. States can also pro-
vide HCBS waiver programs
through Section 1915c waiv-
ers that allow states to target
services to specific populations
and geographic areas; however,
states are allowed to limit
enrollments in these waiver
programs, hence the attention
paid to waiting lists moving
at a reasonable pace in the
Olmstead decision.

Post-Olmstead, the Office of
Civil Rights and the Center for
Medicaid and State Operations
of HCFA issued states guidance
to clarify and support imple-
mentation of the Olmstead
decision. The guidance re-
viewed the Olmstead ruling,
discussed state Medicaid
agencies’ roles and responsibili-
ties, and described avenues for
compliance through use of
comprehensive, effectively
working plans and waiting lists
that move at a reasonable pace.
The guidance recommended
principles and practices for
states to use in developing their
Olmstead Plans, including the
following: the plans should
cover removing barriers and
strengthening service systems
to serve individuals with
disabilities in more integrated,
community-based settings;
people with disabilities should
be actively involved in develop-

Olmstead established that state
Medicaid programs must operate in
ways that comply with the ADA.
individuals could be targeted by detailed assessment and services determination. As broad-spectrum waiver programs were established, states began to add other, more targeted waiver programs for people with HIV/AIDS, brain injury, children with special needs, and others. A common feature is personal assistance services that enable people who need help in performing activities of daily living to continue to live and thrive in the community. These personal assistance services are crucial for younger individuals with physical or mental impairments and elders with frailty and chronic conditions.

Over time, the term long-term care has evolved to become known as long-term services and supports. The change reflects the disability rights philosophy that individuals do not need healing but accommodations (i.e., supports) to meet their needs. This same philosophy has led to person-centered supports in individualized service plans. The focus has shifted from a medical diagnosis and unmet needs defining the need for services to a focus on an individual’s impairments, with his or her capabilities defining the need for supplemental supportive services. The change in terminology from care manager (or case manager) to supports coordinator or supports consultant reflects this change. This evolution in language is moving unevenly across states and stakeholders.

Wielding the Power of Olmstead

Lawsuits have long been used as a catalyst to prompt reforms in the long-term-care system. Prior to the Olmstead v. L.C. decision, individuals with disabilities, disability rights activists, and advocates for community integration had used the court system to further their efforts. Most of those lawsuits alleged violations of the Rehabilitation Act of 1973 or the Medicaid law. The Olmstead decision helped clarify the civil rights issues of community integration for people with disabilities and spawned a series of other lawsuits. As of August 2011, Ng, Wong, and Harrington report eighty-nine Olmstead lawsuits (alleging ADA violations) in thirty-five states and ninety Olmstead-related lawsuits (alleging violations of Medicaid law or of the Rehabilitation Act) in thirty-five states. Of the Olmstead lawsuits, fifty-five have been closed. Of the Olmstead-related lawsuits, seventy-six have been closed (Ng, Wong, and Harrington, 2011).

People with disabilities and disability advocates have also filed numerous complaints based on the Olmstead decision with the Department of Health and Human Services’ Office of Civil Rights. The Kaiser Commission reported an estimated 627 Olmstead-related complaints had been filed with the Office of Civil Rights as of May 2004. Of those, 459 were resolved and 168 were still open (The Kaiser Family Foundation, 2004). Since President Obama launched the Year of Community Living in 2009, the Department of Justice has made Olmstead enforcement a top priority.

Responding to the suggestion in the Olmstead decision and using the guidance provided by the Office of Civil Rights and HCFA, many states began developing formal Olmstead Plans, which identified barriers to community integration, gaps in services, infrastructure needs, and listed steps to transforming the LTSS delivery system. Importantly, the plans addressed elders as well as younger people with disabilities.

Paths to Progress

The progress by states shows wide variation. Twenty-seven states have developed and published formal Olmstead Plans, and eighteen states have developed alternative strategies. As of November 2011,
seven states (Washington, D.C., Florida, Idaho, New Mexico, Rhode Island, South Dakota, and Tennessee) have not developed an Olmstead response (Ng, Wong, and Harrington, 2011).

States face significant barriers in achieving their Olmstead Plan goals. State budget constraints caused by the tech recession in 2001 had not fully recovered when the Great Recession of 2008 overwhelmed state budgets. Accessible, affordable housing remains a significant barrier; the lack of a skilled caregiver workforce hampers expansion; and politically powerful institutional care providers increase the difficulty of obtaining rebalancing legislation or financing legislation.

Grant opportunities brighten the horizon
Prior to the Olmstead decision, HCFA began offering a series of grant opportunities for states to assist nursing home residents who wanted to move to home- and community-based settings. The initial announcement in 1998, Date Certain Grants, garnered twenty applications, with four states (Colorado, Texas, Michigan, Rhode Island) obtaining grants. Disability advocates and state staff designed Colorado’s Deinstitutionalization Pilot Project, which relied on nursing homes voluntarily referring hard-to-transition individuals to single entry point agencies in three counties. The program transitioned eighty-six individuals in one year. State staff and a disability advocate wrote the evaluation report.

The Texas project, called Money Follows the Person, used new legislative authorization (Rider 37) to allow individuals in nursing facilities to bypass the HCBS waiver program waiting lists and transition directly to community living with extensive supportive services (see the interview article with advocate Bob Kafka on page 64). The Nursing Home Transition grant solicitation was repeated in 1999 and 2000.

The New Freedom Initiative
On February 1, 2001, President George W. Bush announced the New Freedom Initiative to promote fully integrating people with disabilities into all areas of society, by increasing access to assistive technologies, expanding educational opportunities, increasing the ability of persons with disabilities to integrate into the workforce, and promoting increased access to daily community life. His Executive Order in June 2001 required executive branch agencies to fully comply with the Olmstead decision; directed the creation of the National Commission on Mental Health; directed the U.S. Department of Health and Human Services to fully enforce the Olmstead decision; promptly implement the Ticket to Work and Work Incentives Improvement Act of 1999; and to implement the consumer-directed Independence Plus Initiative. The 1999 Ticket to Work program expands Medicaid coverage to workers with incomes as high as 450 percent of the federal poverty level. It allows individuals to retain healthcare coverage as they work despite improvements in functioning.

Although the major impetus for expanding consumer-directed services came from the consumer-control philosophy of the Independent Living Movement, elders participated in substantial numbers in the state programs. Funded initially by the Robert Wood Johnson Foundation Cash and Counseling program and later by the Centers for Medicare & Medicaid (CMS), the Independence Plus grant’s participant-directed services expanded rapidly after 2002. Although most advocates believed the majority of participants would be younger adults with physical disabilities, in the Cash and Counseling program many participants were elders (73 percent in Arkansas, 45 percent in Florida, and 53 percent in New Jersey) (see article by Doty and colleagues on page 28). The service delivery initiative pushed so hard by disability rights and community-
living activists brought along older adults in big numbers (Crowley, 2003).

Real Choice Systems Change Grants
In 2000, Congress authorized and in fiscal year (FY) 2001 funded the Real Choice Systems Change (RCSC) Grants for Community Living to help states transform their LTSS systems to rely less on institutional services and to create or expand HCBS options and infrastructure necessary for community integration. The grants program was designed to help states develop the necessary administrative, program, and funding infrastructures to enable individuals of all ages who have a disability or long-term illness to live in the most integrated community setting of their choice, exercise meaningful choice and control over their living environment, services, and service providers, and obtain high-quality services. Between FY 2001 and FY 2010, CMS awarded 352 RCSC Grants, in thirty-nine categories, totaling more than $288 million. The initial grants, described as follows, were relatively modest and intended to promote incremental change in specific key activities.

The initial round of grants were for Nursing Facility Transition programs (twelve states) and Independent Living Partnerships (to five independent living centers). The state Nursing Facility Transition programs accomplished several enduring system improvements that helped create a more balanced service system: new funding for transitions services, increased waiver slots, increased affordable and accessible housing, increased outreach, and increasing collaboration with independent living centers.

As part of the New Freedom Initiative, CMS began the Independence Plus Initiative in 2002. The initiative aimed to use Medicaid funding to promote the self-directing of services and supports. States were required to submit a waiver application for a program that would give individuals the option to control and direct Medicaid funds identified in an individual budget. In 2003, CMS awarded $5.4 million in Independence Plus grants to twelve states to support their efforts to offer a self-directed service option. In 2005, CMS modified the HCBS waiver program application to require states to identify the self-direction elements in their waiver programs.

In FY 2003, CMS expanded its categories of RCSC Grant offerings. Along with Independence Plus grants, they offered Community-Integrated Personal Assistance Services and Supports grants, Money Follows the Person grants, Quality Assurance and Quality Improvement grants, Family-to-Family Health Information and Education Center grants, and Feasibility Study and Development (mostly respite care) grants. There were seventy-three grants awarded that year. In 2004, the focus was on Mental Health System Transformation grants to twelve states.

In FY 2005, the CMS’ focus shifted to larger, more comprehensive grants of greater duration. Three types were awarded: Aging and Disability Resource Center (ADRC) grants, jointly with the Administration on Aging; Family-to-Family Health Information and Education Center grants; and System Transformation grants. In FY 2006, more System Transformation grants were awarded, and in FY 2007 Medicaid Transformation and Person-Centered Planning grants were awarded as well as the first grants for the next large Money Follows the Person initiative (see Reinhard article, page 52). By 2011, ADRC grants had been made to all states, to establish a nationwide system to help consumers identify and access HCBS (see

**RCSC Grants support states to overcome institutional bias and promote community living in the most integrated setting.**
Alexihih and Blakeway article, page 77).

Taken together, these RCSC Grants support states in their efforts to overcome institutional bias and promote community living in the most integrated setting. They started with targeting specific barriers common to states and have evolved to more comprehensive system transformation efforts with states identifying their own barriers to overcome. The goal is to develop systems that are people-centered, inclusive (integrated into the community), effective and accountable, sustainable and efficient, coordinated and transparent, and culturally competent.

Although there is wide variation in states’ achieving these goals, RCSC Grants have greatly accelerated the ongoing system transformation over the past two decades. The average proportion of state Medicaid long-term-care expenditures spent on HCBS in 2001 when the New Freedom Initiative and RCSC Grants began was 29 percent. All states were above 6.4 percent at the time. After less than a decade of grants and other supportive policies, the average proportion spent on community services was 42.7 percent, and in 2008 all states were above 13.9 percent.

Since the ADA’s enactment and the Olmstead decision, the Medicaid service delivery system has steadily transformed, in ways that benefit millions of elders and adults and children with disabilities. 🦓

Dann Milne, Ph.D., is a consultant with Health Policy Consulting in Denver, Colorado.

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Almost fifty years ago, the United States created a new program known as Medicaid to support healthcare for people with very low incomes and assets. Because this healthcare program originally included only institution-based care, it has a deep-seated bias toward nursing home care. The Home- and Community-Based Services (HCBS) waiver programs that began thirty years ago started as a separate long-term-care option in most states, with dedicated and limited funding for which states could apply. Consequently, most states had waiting lists for the waivers, made up of people who needed nursing home-level long-term care, but were entitled only to institutional care under federal law. Many could not wait until a “waiver slot” became available, so they entered a nursing home—often straight from the hospital, but sometimes from home. Once they did so, they crossed a one-way bridge.

Few could return to the community because the waiting lists for HCBS remained long and those waiting in nursing homes often lost the living arrangements and social supports they had before entering the institution. And many professionals, including case managers, nurses, and social workers felt that once people entered a nursing home, they became residents who needed to adjust to their new home rather than work to leave it. Ageism in the United States reinforced this predominant view, stereotyping older adults as fragile people who need protection more than they need independence and control.

States Pioneer Nursing Home Transition
A few states provided two-lane bridges and help navigating a return to the community. For decades, Oregon and Washington deployed state staff to nursing homes to help people of all ages return to their homes or more home-like living arrangements, such as assisted living or adult foster care. They did so for philosophic and budgetary reasons.

Operating under the values of “independence, dignity, and choice,” they assertively sought to align people’s desire to live outside institutions with the financial reality that it was also more cost effective to serve them outside nursing homes. And, these states did not wait for months to talk to people entering nursing homes, or even restrict their discussions to those...
already on Medicaid. For example, Washington assigned state staff to specific nursing homes to talk with every person admitted within a two-week window to assess their desire to leave and what it would take to do so. They worked with the person, family, nursing home, and community staff to organize and implement a nursing home transition whenever possible (Mollica et al., 2006).

Some states looked to these pioneers to create similar nursing home transition programs. For example, New Jersey created its Community Choice Counseling program in 1997 (Eiken, 2003), sending nurses and social workers to Washington for on-the-ground training. To support and learn from these early adopter states, the Centers for Medicare & Medicaid Services (CMS) and the Office of the Assistant Secretary for Planning and Evaluation launched the Nursing Home Transition Demonstration Program, awarding grants to twelve states between 1998 and 2000 (Arkansas, Colorado, Florida, Michigan, Nebraska, New Hampshire, New Jersey, Pennsylvania, Rhode Island, Texas, Vermont, and Wisconsin).

These states could use their funds for almost any direct service or administrative cost that supported the transition of a person from a nursing home back to the community. State and federal officials began to learn how to identify nursing home residents who wanted to return to the community, educate consumers and their families about potential options, overcome practical and attitudinal resistance and other barriers, and develop the crucial infrastructure and supports in the community to make it possible for former nursing home residents to live in their own homes and communities (Eiken et al., 2003).

Many professionals felt that once people entered a nursing home, they needed to adjust to it rather than work to leave it.

Evolving rapidly into a national movement, in 2001 and 2002 the CMS awarded thirty-three grants to state agencies and independent living centers to transition or divert consumers from nursing homes. Independent living centers are nonprofit, community-based organizations that provide services and supports by and for persons with disabilities to help them achieve their maximum potential in their communities. Through technical assistance and peer-to-peer learning, states found that they needed dedicated staff to work with consumers and families to have a successful transition, particularly coordinators to work closely with HCBS programs, public housing authorities, and private landlords. And they needed flexible funds to help consumers establish a community residence, with full consumer engagement in planning their move to the community.

“Money Follows the Person” Becomes the Mantra

While these federal grants helped change the psychological bias of a one-way ticket to a nursing home, especially for older people, they did not provide sufficient funding to overcome the institutional bias so firmly rooted in the financial entitlement to nursing homes alone. The 2003 Money Follows the Person (MFP) grants to nine states kicked off the next wave of nursing home transition efforts, allowing funds paid to nursing homes to “follow” the consumer to the community and pay for the home- and community-based services consumers need to remain independent.

The MFP term gained prominence in Texas as a strategy to deal with those on “interest” or waiting lists for home- and community-based waiver services. Consumer advocates made the successful case to their legislatures that a person in a nursing home was already receiving financial support for their care and would cost the state less if the money could follow them to the community instead. First adopted for fiscal years
2002 and 2003 as “Rider 37,” Texas permitted bills for HCBS waiver services to be paid from the nursing home account, thereby overcoming the waiting list barrier for people already residing in a nursing home.

Extended during fiscal years 2004 and 2005 (as “Rider 28”), officials could transfer funds from the nursing home appropriation to the HCBS waiver appropriation on a quarterly basis for individuals who moved to the community. The program became permanent in fiscal year 2006 by creating an account within the nursing home appropriation to pay for waiver services for individuals who move from a nursing home. Since 2001, the MFP program has helped more than 20,300 individuals who would have been placed on either an “interest” list or a waiting list to be relocated to community settings (Gold, 2010).

Inspired by Texas’ policy change, consumer advocates successfully lobbied for a national MFP Rebalancing Demonstration program in the 2005 Deficit Reduction Act (DRA). The DRA authorized CMS to spend $1.75 billion over five years to implement the program. In 2007, thirty states and the District of Columbia were awarded $1.4 billion in grants implemented through an enhanced federal match for twelve months of services for individuals who spent at least six months in an institution, and who transitioned to a “qualified residence” in the community. These extra federal funds go to the state, not the consumer, to encourage states to invest in the extra effort to help move people who lack strong connection to the community. But, the state had to continue to provide community services after the twelve-month period for as long as needed and for as long as the individuals maintained their eligibility for Medicaid. The 2010 Affordable Care Act (ACA) amended the DRA, extending the MFP Demonstration program through 2016, but permitting states awarded grants in 2016 to use those funds until 2020. The total MFP program now stands at $4.0 billion. Thirteen additional states were awarded MFP grants in 2011, for a total of forty-four grants.

The ACA offered another sought after change. The DRA required a six-month nursing home stay to be eligible for transition assistance under the MFP program. While this eligibility requirement brought needed attention to long-term institutionalized individuals who often need considerable help to find housing and other supports, it did not acknowledge that earlier intervention is critical to prevent long-term nursing home stays that make transition more difficult. It is hard to maintain crucial community connections after six months or more in an institution: people lose their homes, apartments, and connections to neighbors who had been informally helping them in many different ways (Reinhard, 2010).

The ACA expanded the definition of who may be eligible for a nursing home transition under the MFP program to include individuals who reside in an institution for at least ninety consecutive days instead of the 180 days mandated by the initial DRA. (Any days that an individual was in the nursing home receiving short-term rehabilitation services reimbursed under Medicare are not counted toward the ninety-day requirement.) More than half of the MFP states report that the reduced institutional residency requirement will make it possible to transition more consumers (O’Malley Watts, 2011).

**MFP Progress Is Improving**

Although enacted through the 2005 DRA, the MFP program has taken time to launch and demonstrate progress. The CMS required
operational plans to assure appropriate use of funds, and states without a pre-existing, mature nursing home transition program needed time to gear up. The first awards were made in 2007, and states did not begin to actively transition individuals into community settings until the spring of 2008.

Observers note that progress has been slow, but each year the number of participants transitioning has increased as solutions to barriers are identified and technical assistance is provided to help states meet transition goals. Nationwide, as of June 30, 2011, 15,818 individuals have returned to the community, nearly double the number from the year before. More than one-third (34 percent) of these individuals were older adults. Two-thirds were younger persons with physical disabilities (37 percent), developmental disabilities (12.5 percent), or mental illness (2 percent). States vary significantly in their success, with small states like Delaware transitioning forty-four people, while the large and experienced state of Texas transitioned 4,658, which accounts for 29 percent of the total number of people transitioned under the MFP program to date. Five states accounted for about another third of total transitions (Washington, Ohio, Maryland, Michigan, and Pennsylvania) (Denny-Brown et al., 2011).

It is important to note that these numbers do not include nursing home transitions conducted outside MFP program rules. As noted earlier, many states began nursing home transition programs before the MFP program was enacted. Many of them continue to operate these parallel transition programs, including seventeen MFP grantee states (Denny-Brown et al., 2011). Individuals who are transitioned through these parallel programs are not eligible for the enhanced federal matching funding available through the MFP program for one of three reasons. First, they may not be eligible for Medicaid if they have not yet spent down to poverty. Second, they may not have been a nursing home resident for the required ninety days. Third, they may have chosen to move to an unqualified residence, which is typically an assisted living facility.

**Assisted Living Is Not a MFP Option**

The issue of what constitutes a “qualified residence” remains a thorny issue for states trying to help older adults leave nursing homes. Advocates for younger people with physical or developmental disabilities worry that assisted living is another form of institutional care—a nursing home on training wheels. As they lobbied for the MFP program to be part of the DRA, they obtained statutory language that specified that no more than four unrelated individuals could reside together, and that the individual or family member must own or lease the residence, which must have lockable access and egress to living quarters (such as sleeping, bathing, and cooking areas). They felt this definition of a qualified residence would ensure that people transitioned from nursing homes would have housing options that offer maximum consumer control and independence rather than congregate settings that exert institutional control over residents.

The ACA did not change this definition, which arguably codifies the features most desired by younger people with disabilities, but restricts options that many older adults prefer, including assisted living apartments and some adult foster care alternatives.

The restrictions on assisted living may also help explain why MFP states continue to report transitioning more younger persons than they do older adults. Several states that pioneered “balanced” long-term-care systems, spending funds more evenly across institutional and community-based services, have relied on assisted living and adult foster care as important alternative nursing home options. States with mature nursing home transition programs relocate up to 35 percent of their nursing home residents to assisted living (Mollica, 2009). The CMS guidance clarifies
that assisted living may be considered a qualified residence under certain circumstances that enhance consumer control, but it does not address the four-person limit since this is a statutory requirement for eligibility (CMS, 2010). The dilemma remains, even though one could argue that an assisted living apartment in a complex with ten or even 100 apartments could be considered less institutional than a group home with four residents.

**MFP Offers Funding for System Change**

Although enhanced MFP funding for the Medicaid program is not available for all of those who are discharged back to the community, transitioning in any state, the MFP program provides enhanced matching funds to improve their long-term-care systems to make it possible for money to follow the person. For example, states have used funds at the 100 percent administrative federal match level to provide staff to Aging and Disability Resource Centers to support counseling on options and transition help. States are also using funds for caregiver education, better ways to coordinate housing with services, and information system upgrades (Denny-Brown et al., 2011).

**Lessons Are Emerging: Three Program Components**

A formal evaluation of the MFP program is being conducted by Mathematica Policy Research, but lessons are accruing and being published on a regular basis. Highlights include three essential program components: the people, the resources, and the extra services available to MFP beneficiaries (Lipson et al., 2011).

First, and most important, are the people. Nursing home transition is a labor-intensive process that requires patient, creative coordinators who are skilled in interpersonal relationships and communications, grounded in person- and family-centered planning, and knowledgeable about community resources. The most successful coordinators are passionate and dedicated full time to this work. They are comfortable working with both nursing home staff and community-based organizations, especially those in housing. Because this is such a complex role with multiple functions, some states distribute the functions across several different kinds of coordinators.

Some coordinators may focus on outreach to potential nursing home residents who might desire a return to community living, perform a comprehensive assessment, and develop a person-centered plan with the consumer and family (when identified by the consumer as a critical partner in support). They may work hand-in-hand with another coordinator who confirms Medicaid eligibility, gets approval for HCBS waiver enrollment and specific services, and arranges for those services and supports. Yet another coordinator may focus on finding accessible housing. Because a lack of suitable housing is the biggest barrier to a successful transition for many individuals in a nursing home, several states find it helpful to use MFP funds to hire specialized housing coordinators.

Second, the resources to pay for one-time moving expenses, such as basic furniture (e.g., bed, chair, table), food, rental security and utility deposits, and accessibility modifications are crucial. Most people who have been living in a nursing home for three months under Medicaid do not have funds for these basic needs. The MFP rules allow states to pay for moving expenses even before the person leaves the nursing home—an extremely helpful policy that pioneer states in nursing home transition advocated for with CMS.

Finally, the MFP program permits the use of enhanced Medicaid funds for “extra HCBS,”
such as overnight companions, additional hours for a personal care worker and peer support to help people adapt to life outside an institution. States can also use these funds to pay more to providers to help individuals with complex needs (Lipson et al., 2011).

Barriers and Gaps Are Clearer
The shortage of affordable and accessible housing remains the chief challenge to successful nursing home transition. The supply of HCBS is also problematic, especially for people, including those with dementia, who require specialized services. Particularly in rural areas, the shortage of direct-care workers limits the ability to serve people in individual apartments. In the current economic climate, cuts to Medicaid benefits and payment to providers exacerbate these challenges. Reductions in state staff also compromise stable and effective program leadership and coordination.

What Lies Ahead
Money Follows the Person can be viewed from two perspectives: where does the funding come from and where does the person come from? The first MFP perspective focuses on an overall funding strategy, often called a global budget, which supports individuals’ choice of settings through pooled appropriations across settings. Pioneering this approach thirty years ago, Oregon used a pool of money in one long-term-care global budget that could be used to provide support in the community or the nursing home, with a major goal of helping people remain at home whenever desired and feasible. In this model, the person does not need to start from a nursing home to get support in the community, but rather can be diverted from institutional care. The second MFP perspective, codified in the DRA and ACA, focuses on individuals who must move from an institution to get support for community living (Mollica et al., 2006).

Ideally, states could support the first MFP perspective, the combined nursing home diversion and transition approach that Oregon initiated thirty years ago. The second MFP perspective might be considered a pragmatic work-around to promote community living. But it holds the promise of expanding the infrastructure for HCBS through enhanced federal investments and state peer-to-peer learning on how to balance long-term service and supports systems.

The current economic challenges and rapid evolution toward managed care will have significant effects on the MFP demonstration, which will continue for almost another decade. States that move toward managed long-term-care contract with organizations to provide a package of benefits on a risk basis, giving these organizations a specified amount to provide long-term care to eligible Medicaid beneficiaries. Some states do not include nursing home care in risk contracts, others include up to 180 days in a nursing home within the managed care contract, and some include the full risk of nursing home placements (Summer, 2011).

Given the limited experience that states have with both managed long-term care and MFP, it is not clear how these two programs will interact. If the managed care company has full risk for nursing home care, the incentive is to divert or transition whenever possible. Creative housing and service arrangements may emerge, fueled by the managed care organizations themselves. In states where managed care organizations have no responsibility for nursing home care, will the state need to operate an even more robust MFP program to ensure that nursing home residents have an opportunity to return to their communities, if desired and if it is possible? And what happens in states that fall in between these incentives?

While there is no doubt that people who need long-term services and supports want to live in their homes and communities, it is premature to conclude that the MFP program
will be the dominant mechanism to help them do so. As states consider major changes to their programs and financial arrangements, it will be important to consider all potential strategies to maintain the momentum to build two-lane bridges. Older adults may choose nursing home care for some period of time, but some may desire a return trip home.

Susan C. Reinhard, R.N., Ph.D., is a senior vice president at AARP, directing its Public Policy Institute and the Center to Champion Nursing in America Washington, D.C. She led the redesign of long-term services and supports in New Jersey, and technical assistance for states across the country for the Centers for Medicare & Medicaid Services.

References


References
For more than twenty years there has been ongoing discussion in the United States about “rebalancing” the states’ long-term-care (LTC) systems. This statement implies such systems were at some point balanced, became “unbalanced,” and now need “rebalancing.” Instead, most states have never had a system of long-term-care services. Some have offered limited access to a few long-term-care services; but in many states a nursing facility is the only long-term service anyone, especially low-income individuals, has access to. The nursing facility program is the only mandatory long-term-care service in Medicaid.

Over the years, Oregon and Washington have been viewed as having the most balanced long-term-care systems for older adults in the United States. Both states’ systems have provided consumers, including older consumers, with real choice in types of long-term-care services. Both states also have made efficient use of state and federal funds available for long-term care, and have done a good job controlling cost, while offering more long-term-care options. Consequently, most consumers of long-term-care services in the two states are served in home- and community-based settings rather than in institutions.

Most people, even those with a need for long-term-care services, prefer to live in a home-like setting. In my view, a “balanced” long-term-care system is one that provides an array of services to meet individual needs and preferences. In Oregon and Washington, the balanced long-term-care system has no waiting list for services, and consumers and their families have viable access to a quality array of services.

In a balanced system, no single long-term-care service is more important than another.

In a successful balancing act

So why have Oregon and Washington been successful in “balancing” their long-term-care systems? I’d argue it’s because those trying to improve the long-term-care systems in Oregon and Washington saw their role in a different way.
As a result, the Oregon and Washington systems became more like each other and less like the rest of the country.

Dick Ladd was the point person for LTC in Oregon, and I had the same responsibilities in Washington State. We developed a strong friendship and became somewhat competitive in seeing who could develop the best long-term-care system. Also we shared a strong sense that we should develop a long-term-care system that would give consumers a choice regarding the type of service delivery system they wanted.

Dick and I both wanted to develop a long-term-care system we might be willing to use if ever we needed such services, hoping to develop a system that met individual needs. We often talked about quality of life issues such as sharing a bedroom or a bathroom, what time we got up in the morning, and what we watched on TV. We had both been around long-term-care services long enough to know most folks needing long-term care and entering the “state system of services” would be at a point where someone else was making basic decisions for them. To receive their needed long-term-care services, individuals usually had to enter an institutional setting.

So we set out to develop long-term-care systems that would deal with such individual quality-of-life issues. After getting out of college at age 25, I decided that I would never again share a bedroom unless I was in an intimate relationship. In the state of Washington and most other states, if you entered the long-term-care system you were often assigned a roommate—a person you did not know and very possibly did not like. I disliked this concept and assumed many people with a disability felt the same way. I wanted to develop a long-term-care system that did not require you to have a roommate. My view on this partly drove the development of the Assisted Living Program in Washington State.

So how did we use our philosophical framework to develop the Oregon and Washington long-term-care systems? What factors have made Oregon and Washington different and perhaps better than many other states in the long-term-care business? What makes the difference is a clear vision and plan, based on core values widely disseminated and discussed in both states, and organizational arrangements that make it possible to implement those values.

**Planning with a Progressive Spirit**

For years, both Oregon and Washington had a tradition of a very progressive social-service
system that attempted to meet their citizens’ individual needs: both states began planning and developing their long-term-care systems in that same spirit. There were discussions with elected officials, state staff, consumers, families, and providers that shaped a set of core values to drive the planning, development, and operation of a balanced long-term-care system (see the sidebar on page 60).

In both states, the core values were discussed and developed in a series of meetings and public hearings. The essence of the core values was also included in state legislation implementing various parts of the long-term-care system of services in each state. The more difficult step was to put into place components of the long-term-care system that would actually give consumers viable access to the services they wanted and needed.

**Cutting Through the Bureaucracy**

In our experience, the first and most important factor needed to achieve a balanced state long-term-care system is having a single organization in state government to plan, develop, and operate that system. This single organizational unit in state government is responsible for all parts of the state long-term-care system, including all state funding, as well as the Older Americans Act, and Medicaid funds for long-term care. This single unit sets policy and direction for the long-term-care system, and is held accountable by the governor, the legislature, the public, and consumers of long-term-care services.

Crucially, the Medicaid long-term-care services had to be in this single organizational unit because Medicaid dollars are so critical to operating a state long-term-care system. Most other components of system development could not have happened if our two states had not developed a single place in state government to manage the long-term-care system. Having all of the long-term-care policy, budget, and eligibility issues in one place allowed our states to be strategic in planning, development, and system operations.

The same authority was responsible for both the nursing home and the home- and community-based services (HCBS) budgets, and could make tradeoffs toward emphasizing the latter. It also meant the same state organization was responsible for care coordination and case management in nursing homes and in HCBS.

**Features of the Oregon and Washington systems**

Important features of the Oregon and Washington long-term-care systems that are located in one administrative structure in the state governments are as follows:

- **A single point of entry for consumers to enter the long-term-care system.** This “front door” determines functional and financial eligibility for long-term-care services using a standardized assessment, and controls access to the state and federally funded long-term-care service system. The data collected are used to manage the long-term-care system, and keeps state decision-makers aware of costs and expenditures. In Oregon, area agencies on aging operated this front door through a contract with the state government. In Washington, state employees working directly for the Washington Aging and Adult Services Administration operated the front door.

- **A fast and timely standardized way to determine financial eligibility for services funded by the state and Medicaid.** In Oregon and Washington, Medicaid eligibility was determined in hours or days rather than weeks or months, as in many other states, which is an important element of the Oregon and Washington long-term-care service delivery systems. Most providers are unable to provide services to someone who is not yet declared Medicaid-eligible. In most states, nursing facilities are the only long-term-care providers who will take a client who is not yet declared Medicaid-eligible. Most home and community service providers are unable or unwilling to provide service to a consumer who is not yet declared eligible by the Medicaid system.
• A statewide case management system to provide assistance and oversight for the consumers of long-term-care services. Case management services help consumers make the best use of available long-term-care services and coordinate care plans for health, safety, and best use of resources. Case managers coordinated services for Medicaid clientele in nursing homes as well as in HCBS. Both states were then free to develop flexible delivery systems—client-employed homecare in Oregon and Washington—without having to resort to home health agencies to manage cases for HCBS, as happened in other states.

• A process for assuring quality oversight and enforcing quality standards throughout the long-term-care delivery system. Professional quality surveyors and case managers provide the quality oversight.

• Training and support for various providers of long-term-care services. This includes fair rate-setting and contracting processes.

In most states, components of the long-term-care system are scattered within the government bureaucracy.

• An ongoing process for developing resources to meet growing long-term-care-services demand. Both states recruit and train providers to be part of the state’s long-term-care delivery system. Oregon and Washington have worked closely with nurses on delegation; nurses can delegate certain tasks to non-nurse care providers, allowing for quality and cost-effective services to be offered in homecare settings. In both states, family members can be paid for providing services to consumers of long-term-care services if this is the consumer’s preference.

• A well-organized, articulate, sophisticated group of consumers and providers who advocate for a quality long-term-care service system to meet individual needs. In both states, the state government agencies that operate long-term-care systems meet regularly to provide information and listen to statewide coalitions of consumers, families, and providers who advocate for the continual improvement of the state long-term-care system.

A scattered approach in most states
In most states, these component parts of the long-term-care system are scattered in six or more places in the state bureaucracy. A different branch of bureaucracy controls each part of the system, and has a stake in controlling or protecting the part of the budget and services for which it is responsible. While there may be efforts to coordinate between different state offices, it never seems to work well, and it creates gaps in the long-term-care system, making it difficult or impossible for consumers to navigate and receive services they need.

Positive impacts on private-pay individuals
While both state systems were put in place to serve the low-income population (those primarily eligible for Medicaid), both states have also had a positive impact on long-term-care services for those paying privately.

The long-term-care systems developed in both states have served many private-pay individuals. The best examples may be adult family homes and assisted living or boarding homes that were developed and are regulated by the publicly funded long-term-care system. In both states, there are now more private-pay, long-term-care consumers living in such homes than there are Medicaid-funded clients. These private-pay clients have benefited from the development and state regulation of these services.

The Winds of Change
Both Oregon and Washington long-term-care systems have functioned fairly well over the last twenty years, providing consumers real choice in the type of service they want and need and keeping state expenditures within
reason. However, there is change in the wind. Oregon and Washington, like most states in the country, have been hit with large budget deficits that are severely impacting their long-term-care programs.

The largest segment of the long-term-care caseload is served in preferred and less expensive home-based and community-care settings. Because both states have noticeably reduced the caseloads and expenditures for nursing facility care, there are not many financial gains yet to be made this area. Because of considerable budget deficits, the governors and legislatures in both states have increased eligibility and reduced caseloads for long-term-care services, making significant reductions in the long-term-care service system.

With continuing budget deficits in both states, more major cuts are still under consideration; this will mean many people who have been eligible for service in the past will no longer be eligible. Those who will still be eligible may be placed on a waiting list.

Structural changes are also being considered in both states. Most leaders involved in setting up and operating the long-term-care systems are no longer working in state government. Those now in charge seem not as focused on consumer choice driving the system.

Both states also are in the process of moving Medicaid programs away from aging and long-term-care administrations, and the two programs will be housed in different state agencies. The stated reason for this is to focus on attempting to have all state healthcare purchasing in one place. There seems to be little understanding by decision makers in the two states of the potential negative impact on the state long-term-care systems if and when these moves occur.

In Washington and Oregon, the Medicaid long-term-care budget was administered in one state agency; this was a major element of the success of the two programs. While there are more mothers and children served in state Medicaid programs, the largest amount of Medicaid money is spent on the older and disabled populations served in the state long-term-care programs.

There are also very serious discussions going on in the two states about moving the long-term-care systems into a managed care approach. If the managed care efforts move forward, the long-term-care system could be contracted out to for-profit corporations to operate the long-term-care service system.

Sometimes change is good, sometimes it is not. Time will tell.

Charley Reed, a member of the AARP Board of Directors, is a long-term-care consultant for his firm, C.E. Reed and Associates, in Olympia, Washington.
Tell us about ADAPT and its goals.
ADAPT is the largest all-volunteer, activist, national, grassroots, direct-action, disability rights organization in the country. We organize people with disabilities of all ages, their family members, attendants, and advocates to affect social change. Currently, our main issue is to reverse the institutional bias in the long-term-care (LTC) system. ADAPT believes that people with disabilities of all ages can live in the community with dignity when adequate services and supports are provided. The chant “Our Homes, Not Nursing Homes” encapsulates this vision.

Another tenet of ADAPT advocacy is to promote services and supports based on each person’s functional needs, not on a disability label or age. We recognize the different ways older Americans approach getting and using services, but believe the delivery of many services can be identical regardless of age or disability type. ADAPT believes a silo mentality has corrupted the delivery of services and has promoted an us-against-them mentality.

How well has ADAPT succeeded in reversing institutional bias?
ADAPT began its advocacy to reverse Medicaid institutional bias right after the Americans with Disabilities Act was passed in 1990. We never imagined that this would be such a long struggle. Though we have not attained the ultimate goal of people having an equal chance to choose HCBS, we’ve had significant wins. Most importantly, the debate is no longer [about] if there is an institutional bias, but how to reverse it—a major political shift.

Our first win was the funding of the Real Choice System Change (RCSC) Grants allowing states to apply for funding to reform their LTC systems. The idea for these grants came from a section in the Medicaid Community Attendant Services and Support Act, a bill originally drafted by ADAPT (now called the Community Choice Act). The initial funding began with a $75 million annual appropriation, but by 2012, RCSC had spent over $300 million for state systems reform.

The next major victory was the inclusion of $1.75 billion dollars for the Money Follows the Person (MFP) Demonstration in the Bush budget. This money (delivered through an enhanced federal Medicaid match to states) has helped thousands of residents of nursing homes and other institutions move into community settings. The healthcare reform bill of 2010 added more than $2 billion to the MFP program, and included two other significant components: the Community First Choice Option, which allows people eligible for nursing home or other institutional services to choose HCBS, with states receiving 6 percent enhanced Medicaid match; and a Home- and
Community-Based Services Incentive Option, which also offers an enhanced Medicaid match as a carrot for states to select it.

The forecast for Medicaid-funded services in 2012 is gloomy, but if we are strategic and work together as aging and disability advocates, we can make reforms in the Medicaid program to improve service delivery. One area for reform is the disparity in HCBS waiver use between the aging-physical disability community and the developmental disability community. Seventy-five percent of all waiver dollars are for people with developmental disabilities. Recent rule changes allowing states to develop waivers for all populations, regardless of label, may bring more equity and functionality to the long-term services and supports (LTSS) system.

Tell us about using an obscure part of the Nursing Home Minimum Data Set (MDS) to identify residents who want to leave nursing homes.

After the Supreme Court Olmstead case held that people with disabilities have a right to services in the “most integrated setting,” we looked for ways to implement the decision at the state level. Because Texas is fiscally conservative, we needed to fund community services for folks leaving nursing homes without being seen as budget-busters. A friendly legislator attached “Rider 37” (budget instructions) to the budget of the Department of Human Services that said the money appropriated for people in nursing facilities would follow them if they left the facility for the community (a precursor to the federal MFP program just mentioned). Given its budget-neutrality, Rider 37 sailed through the legislature.

Two practical questions followed: How to identify people who wanted to move to the community; and how to facilitate their transitions. I was amazed to learn that Item Q1a on the MDS quarterly assessment, which nursing homes are required to complete on all residents, asked if the

In 1986, Bob Kafka (left), and another ADAPT member, demonstrated in Houston, Texas, to get the city’s Metro to install bus lifts for disabled people.
resident wanted to move to the community, and previously unused results showed 20 percent of
nursing home residents in every state wanted to leave. We realized we needed relocation specialists
to work with identified individuals to build plans to leave nursing homes. Because of privacy con-
cerns, we needed to get a Data Use Agreement from CMS before state agencies could reveal the
names of residents wanting to leave.

What do you see as the main differences in the way HCBS services work for older
people versus younger people?
The various identity silos we stick ourselves in (aged, physical disability, intellectual disability,
developmental disability, brain injury) have caused major administrative and delivery problems and
inequities in meeting the needs of the growing HCBS clientele. The country has more than 300
HCBS waivers; some states have ten-plus waivers. Each waiver has its own provider-base advocacy
group that promotes its uniqueness and lobbying efforts at state legislatures.

Why are consumer-controlled services targeted for younger people, while the traditional agency
model is okay for elders? Medicaid managed care is on the rise for elders and people with physical
disabilities, but those with a label of “developmental disability” remain in a fee-for-service system.
People with a cognitive disability acquired before age 22 can receive a considerably more enriched
package of HCBS services than can a person with identical needs who acquired a brain injury, had a
stroke, or was diagnosed with Alzheimer’s. Not only do services vary, but the agencies at the state
level administering these services are also separate.

Though the philosophical basis for the Aging and Disability Resource Centers (ADRC) is to pull
these disparate entities together, ADRCs are mostly driven by aging networks, with some support
from the communities of people with physical disabilities. The communities of people with develop-
mental disability and mental health disability largely do not participate.

What differences did you notice in professional approaches to healthcare and
HCBS for your father in his old age, compared to approaches offered to younger
persons with similar disabilities?
After a stroke, my dad moved from Fort Lauderdale, Florida, to Austin, Texas. At first he preferred
not to live with my wife and me, so we found him a one-bedroom apartment in an assisted living
facility. What struck me was the number of people inching along the halls using walkers with bright
yellow balls on the back two legs to avoid sliding. Not a wheelchair in sight. I knew from personal
experience as a “walking quadriplegic” that using a wheelchair for long distances and crutches for
shorter jaunts made me much more mobile and independent, and conserved time and energy
without reducing my overall functional capacity.

As my dad’s diabetes advanced, he entered the hospital to have his legs amputated. They
wanted to put diapers on him to keep the bed dry. I suggested an alternate solution and a battle
royal ensued. Only my continual ranting and raving—and finally a threat of legal action—made them
capitulate. Upon discharge, my dad moved in with us and we arranged for him to get on the Texas
HCBS Waiver program, which provided him with needed attendant services.

The next hurdle was to get him a motorized wheelchair. With no legs, and one arm affected by a
stroke, he had to depend upon an attendant to push a manual wheelchair. You’d think he was a
perfect candidate for a motorized wheelchair. You would think wrong! Another battle began
between me and the durable medical supplier. I prevailed, but I wondered how many older people
are unnecessarily made dependent by professionals.

These personal experiences taught me that there needs to be ongoing education of medical and
rehabilitation professionals and social workers on the commonalities of needs of older and younger
people with disabilities.
What do you say to folks who say that 80-year-olds and 90-year-olds do not have the energy or stamina to manage attendant services? And what do you say to those who tell you that elders prefer nursing homes?

One word best describes what I want—and what I believe all adults, of any age, with or without a disability, want: control. This doesn’t mean we have to do everything for ourselves. We can use assistance with activities of daily living or cognitive issues, yet retain control over our environment and circumstances. Sometimes the independent living philosophy is erroneously interpreted to mean doing everything without help, and without care agencies. But having consumer-directed services doesn’t require that consumers become small employers. Consumer-directed means consumers select their personal care assistants, direct their activities while the assistants provide the services, and that they can dismiss assistants if their work is unsatisfactory, regardless of who the employer of record may be.

When I hear the argument that older people want to enter nursing homes, I ask what alternative options they were offered. The HCBS service system is so underfunded that to say older people had a real choice is questionable. When you look closely at people in nursing homes you find that their social support system has broken down. Physical, cognitive, and behavioral health needs are high, and services addressing those needs are minimal or non-existent in HCBS programs for older folks. If we reform the LTSS system to address a person’s needs rather than their age or particular disability, fewer will “choose” nursing homes.

At one time, you considered assisted living to be just another form of institution—more restrictive than you would wish for people with disabilities. Yet for many elders, assisted living is often seen as an escape from an institution. What are your thoughts about it?

My views on assisted living are evolving and, I must admit, inconsistent. My initial stereotypical view was that all assisted living facilities were wings of nursing homes with differences in name only.

My personal experience with my dad, however, changed my views. His assisted living setting hardly differed from the apartment where we grew up in the Bronx: he had a one-bedroom apartment with a small kitchen area and bathroom. He had a key to the apartment and could come and go as he pleased. There were no mandatory activities and the only institutional aspect to the place was being required to sit at the same table in the group dining room at meals. My dad needed some home health services while he was there, but he could choose any agency he wanted to provide him with services. It seemed that the vast majority of the people in my dad’s location (80 percent of whom were women) had chosen it for social reasons rather than to get help. The assisted living label covers a wide range of living arrangements, from apartment-like to more institution-like situations.

I now sound a new note of caution. Assisted living is popular in the older community, and as demand has risen, it has attracted more providers. Many of these providers are the same large corporations that own nursing homes. It seems that assisted living is morphing into an industry where providers appear to care more for the bottom line than about the clientele. Though assisted living advertises itself as a housing option, some in the industry lobby against policies like residents having keys to the front door and a lease. It is almost like they fear the application of the Fair Housing Act. Some assisted living providers promote themselves as housing, but fall back upon calling themselves “facilities” when it serves their purposes.

I’d say assisted living is neither the solution nor the problem. We need to pursue an aggressive policy for funding aging in place and give older people real alternatives to congregate living. This competition will assure that families and individuals get a real option to choose HCBS. Currently, assisted living provides competition to nursing homes. Our non-congregate community support
system is not enriched enough at this point, so families and individuals don’t feel comfortable that HCBS will meet their needs; thus HCBS gives assisted living weak competition. It is meeting a growing need in lieu of nursing homes, but our focus should be on changing the situation where congregate solutions are still the default.

Now that you yourself are over sixty-five, do you have any worries about whether services could deteriorate for people who age with a disability? For those relying in part or totally on publicly funded services, are there any advantages, HCBS-wise, when someone with a long-standing disability turns sixty-five?

Now that I have hit sixty-five and am getting over the traumas of being on Medicare and most of my friends becoming grandparents, I am left with the problem of what to call myself. Am I a person with a disability, a baby boomer, an aging hippie, a greedy geezer, a senior citizen, or just a closet policy wonk masking as a disability rights activist? Regardless of labels, we all face the possible erosion of publicly funded services and supports we fought so hard to establish over forty-five years. Entitlements like Social Security, Medicare, and Medicaid will fundamentally change in the next decade, and funding for discretionary programs (such as for those in the Older Americans Act) is threatened.

As an advocacy community, we must address these challenges: will we circle the wagons based on our individual identity-based programs and attempt to stave off changes? Or will we work together to promote reforms in critical programs that promote health, community integration, independence, and dignity? If ever the disability and elder communities needed to work together, that time is now. Regardless of the outcome of the 2012 elections, the economic realities will dictate political actions.

Our organizing priorities need to be at both national and state levels. Action on Medicare is federal, but for those concerned about HCBS, the way Medicaid is reformed is of paramount concern. Most Medicaid reform proposals give states even more flexibility to escape restrictive federal rules and regulations. The block granting of fixed sums to states is the most popular federal reform proposal from conservatives. We see similarly motivated efforts of state legislatures that submit 1115 waivers applications (i.e., Research and Demonstration Waivers) instead of the usual HCBS waiver applications to achieve the flexibility that they say will control their exploding Medicaid budgets. Also, under Medicaid, more states are going to managed care delivery systems for acute care and LTSS to get budget certainty in the Medicaid program.

State flexibility can be positive if its intent is to achieve more service coordination, more wellness and prevention, less institutionalization, and more HCBS. However, if the flexibility is sought just to save money by reducing critical services, cutting provider rates, and eliminating people from the programs, obviously we must fight this package of “reforms.”

In September 2011, ADAPT organized a My-Medicaid-Matters Rally, co-sponsored by ninety-four other national disability, aging, children, religious, labor, and civil and human rights organizations to highlight the positive role Medicaid plays in American’s lives. We hope that the energy generated by the thousands of people in D.C. would convert to My-Medicaid-Matters campaigns at the state level. The “reform” train has left the station and we must be on it or get run over by it!

The differences between the aging and disability communities are breaking down, and logic, self-interest, and the power of working together are growing. We are more alike than different. This aging hippie is pleased to say, “I am old, have a disability, and am proud of it!”
Lessons Learned While Caregiving: Can Private Resources Cover HCBS?

A conversation with Keren Brown Wilson

Keren Brown Wilson is founder and president of the Jessie F. Richardson Foundation (named for Wilson’s mother) in Clackamas, Oregon. The Foundation aims to improve housing and services for older adults in the United States and abroad, and embraces approaches that enhance internal capacity and sustainable solutions to problems impacting elders’ quality of life. In this dialog with Guest Editor Rosalie Kane, Dr. Wilson, an experienced gerontologist, shares her personal stories of decades of family caregiving for her three sisters.

Rosalie Kane: While you were still a graduate student, your mother received care in a nursing home after a serious stroke. Were there no other care possibilities for her at that time?

Keren Brown Wilson: When my mother first needed long-term care after her stroke in 1969, my sister and I—the two youngest children and the only ones nearby—were living in a rented room, working and attending college. Mother was living in a rented apartment, working as a retail clerk, and had little money. The care choices were limited because of her finances, and because there was no community long-term-care system. Families would move a hospital bed into a downstairs room, and if resources permitted, secure a private duty nurse on the doctor’s recommendation. Nursing homes were typically converted from existing homes for the aged after the passage of Medicare and Medicaid in 1965. The construction of newly licensed nursing homes had just begun, home health and hospice care did not exist, and rehabilitation services were not well developed. My mother never wavered in her desire ‘to go home,’ which meant anywhere she could be in charge of her own life.

RK: What did you learn from this early introduction to long-term supportive services?

KWB: First, I learned that needed services were not covered by public payment programs; Medicare simply did not cover long-term nursing home stays. My mother was eligible for financial assistance and Medicaid because her income and assets could not cover the nursing home bill, rendering her “medically needy.” But many things she required for her care were not...
covered under Medicaid. The personal allowance allotted to those whose nursing home care was subsidized by Medicaid was just a few dollars a month—an amount too low to pay for uncovered healthcare expenditures like orthopedic shoes, dental care, and eyeglasses, let alone personal care requirements like haircuts, clothing, toiletries, and other items for which the allowance was intended. These last were provided by relatives, through the kindness of strangers, or often, not at all.

I also learned that it was hard on everyone—the patient, their family, and the staff—when a resident wouldn’t comply with the group setting’s many rules for daily living: residents’ personal values seemed to carry little weight. I saw that residents had better have someone ready to do battle with ‘the establishment’ over silly things such as bedtimes, or more reasonable things like adherence to a prescribed diet.

But the most important lesson I learned was that the definition of quality care was elusive and clearly in the eye of the beholder. Early on, I found ‘quality checklists’ for evaluating available nursing homes. In my mother’s case, her definition of quality was not about numbers and types of staff, inspection results, activity programming, or even the facility being in good repair. Her definition was about her values. I realized this when she moved herself from a brand spanking new nursing home—one with the highest professional rating—that I had selected, to the top floor of another licensed nursing home without an elevator. Frustrated, I asked her why she had done this. She said, ‘They let me live my life.’

This was the second part of that lesson: my mother’s inability to ‘have a life’ in the other nursing home was not because of a willful decision by the staff; rather it was because the staff either did not care or lacked the skills to appropriately support my mother’s choices. This truly was my Eureka! moment. Why couldn’t these people see how important it was to put people needing care at the center of their care decisions?

**RK:** Despite more than a decade of disability and chronic illness, your sister Vee lived in her home until her death. Tell us about her, about her care over the years, and what you learned from that experience.

**KBW:** In 1985, about seven years after our mother died, Vee had the first of several strokes. This was just after she had retired from more than thirty years working in a manufacturing plant. She lived with the strokes’ effects for fifteen years. Many things had changed since my mother’s stroke in 1969. Oregon began the nation’s first HCBS Medicaid waiver program in 1982, more extensive in-patient and outpatient rehabilitation programs were now available, and I had built (and was operating) my first assisted living setting. Another new thing was ‘care conferences,’ where medical professionals would meet with patients and their families to plan care.

I was called into Vee’s care conference while the medical team was planning her post-hospital care. One reason they called me was because she wasn’t cooperating with their plans to discharge her to a skilled nursing facility for rehab. Vee had decided instead to go home. They thought I, as a Ph.D. and fellow professional, could talk some sense into her. I’ll never forget it: I felt overwhelmed by the big conference table and the number of people sitting there—all of them wearing white lab coats while Vee, dressed in her hospital gown, sat in her wheelchair at one end of the table.

Each person made a self-introduction and gave their professional credentials. They never looked at Vee, but focused on me, telling me why my sister needed to go to the nursing home.
looked at Vee, but focused on me, telling me why my sister needed to go to the nursing home. Finally, they asked for my opinion. I couldn’t say what I really thought: that the battle was lost because they had not involved Vee in the discussion. They hadn’t asked her why she didn’t want to go to rehab or why she wanted to go home. If they had, they would have learned that her reasons included responsibility for a disabled son, five cats, and two dogs—and her smoking habit. If I hadn’t been so overwhelmed, I would have asked those professionals why they were acting like Vee wasn’t even there. I would have told them that she had reasons for fearing rehab in a nursing home. I would have asked if Vee could do rehab at home.

For the first several years Vee managed at home, sleeping in her converted dining room and helped mostly by her live-in disabled son. Eventually she was hospitalized due to the effects of medication mismanagement. By this time she had a case manager who said Vee couldn’t come home unless there was a plan to keep her safe.

Though the HCBS system had expanded by 2000, it was far from a good fit for Vee. Home-delivered meals were frozen, so they remained uneaten. Homecare workers could only do certain tasks—cleaning cat boxes and sorting through bills were not included. Personal safety systems only work if you keep them handy. Getting to the bathroom doesn’t mean you can properly clean yourself after toileting. I finally found a live-in helper, but how to handle coverage during the helper’s time off was a challenge for the rest of Vee’s life.

I learned that money can’t always buy your dream long-term services, but it helps you get what you need for a square peg being forced into a round hole.

**RK:** Your sister Bonnie lived at home with her husband through a long siege of congestive heart failure punctuated by crises and hospitalizations.

**What was her situation and what lessons did you learn from it?**

**KBW:** Bonnie was the baby in our family. When she was born, she was what used to be called a ‘blue baby.’ Her health problems began to surface in early adulthood and escalated after Vee died in 2005. When I got a call saying Bonnie was in the ICU and not expected to live, I raced over. Told that she had hours to live, she then told me what she wanted after death. Over the next five years, she was given a death sentence many other times. Bonnie’s illness was long and serious, but each successive pronouncement of near death was met with some skepticism.

Bonnie was lucky to have had more than thirty years with one health insurance company—an HMO with an excellent reputation. She was not so lucky that her husband’s cancer and her extended illness made their premiums and co-pays much higher than they could afford. Before she died, they were forced into bankruptcy: Bonnie was just too young for Medicare and too rich for Medicaid. Her husband kept a failing business going just so they could keep their coverage, but this drove them further into debt.

I learned that even if you can pay a premium, you couldn’t necessarily find insurance—at any price. Moreover, insurance didn’t pay for many things—like an adjustable bed so Bonnie could sit up to breathe. It didn’t pay for in-home care, or get my sister to the weekly doctor, lab, and clinic visits. We came up with a patchwork of family, friends, and neighbors to help, but her illness was long and her needs increased over its five years.

In those years, some things changed in how hospitals did care. They introduced hospitalists—doctors who have a hospital practice only and theoretically coordinate all the specialists involved in a hospitalized patient’s care. This probably has more advantages for the doctors than for patients and their families, who must deal with doctors who aren’t aware of the
human dynamics and likely won’t be involved long enough to learn them. By then, healthcare professionals had also come up with the idea of ‘patient-centered goals.’ But those goals were focused on managing pain or reducing the level of oxygen support. They didn’t include things like getting your dog approved for a visit, or getting your toenails cut.

The hardest lesson was giving up. When you dodge a bullet for so long, staying alive becomes the goal. Every hospitalization brings you face-to-face with choices and consequences. Our technical medical advances far outstrip our ability to evaluate decisions. We don’t know how not to stop trying to keep alive those we love.

RK: After your older sister, Donna, became widowed, she came to live with you in Oregon. At that time, she was healthy and active—but that changed. What were the challenges and lessons you learned during Donna’s last years of life?

KBW: I called Donna my ‘sissy mom’ because she was largely responsible for me before I started school. This forged a particularly strong bond between us. Even though I was younger, she often looked to me for help when she felt overwhelmed. Donna was also the organized one. She remembered birthdays, made beautiful Christmas packages, had a place for everything.

After her husband died she was lonely, fearful, and struggling financially. It was an easy decision to ask her to live with us. My husband and I needed someone to help us have a more balanced life. The first several years she lived with me she was a godsend, helping with my other sisters and making me look like Wonder Woman. In time, though, I realized that her organization was how she dealt with severe anxiety.

Her health had never been great. She needed a lunch pail to carry her medications and a rolling cart to hold her oxygen. Still she whirled when she worked at the things she loved: cooking, cleaning, creating. But in the fall of 2006 she started staggering; the diagnosis was compressed vertebrae in her neck requiring surgery. After the surgery she was discharged, over my objections, on a Friday night, three days before Christmas, to a regular skilled nursing home for rehabilitation. Within a week she was re-admitted to the hospital. She had been discharged too soon to a setting of convenience rather than a specialty rehab for her type of condition. After proper rehab, she made remarkable strides, and came back to live with me.

Then she had a cerebral hemorrhage. That was the beginning of the end. At the nearest hospital, the young ER doctor saw her as just another old person. He didn’t start the recommended treatment, but suggested they give her comfort care. Learning a little after all my experiences, I asked for a second opinion. They transferred her to a larger hospital, where the doctor neglected to tell the consulting specialist she was on blood thinners. If I had elected for surgery, she would have bled out. As it was, the right treatment wasn’t started for hours. The result left Donna bed-bound, and unable to do many things for herself.

One Sunday morning I walked into her room and she was burning up with a fever so high they had packed her in ice. She hadn’t been closely looked at for hours. They assessed her and said she had no rehab potential, and wasn’t eligible for the skilled nursing care under Medicare. They were ready to discharge her with pneumonia and a urinary tract infection. I requested that her record show that she was being discharged over my objections.

Life wasn’t through with Donna yet. She went to a medical foster home. (In Oregon, an adult foster home is an HCBS setting in a private home for five or fewer people and a medical foster home is one where the proprietor has some formal healthcare qualifications, such as nursing). There she learned to swallow, talk, walk, feed, and dress herself again without the benefit of a rehab. But after all of this, she fell and fractured her hip.
This time she stayed on the hospital call light so much I had to spend the night. After a few days in a skilled nursing facility, the facility called to say they were sending her to a locked unit. At my insistence they sent her to another hospital that was better prepared to deal with her problems. My years of experience and the development of more choices made it easier to decide what to do.

But the biggest surprise was Donna. The person who had so fiercely struggled to overcome her problems was now a shadow of herself, afraid of everything. Even though we were able to get her to the point physically where she could live in an assisted living apartment in the company I now directed, she was done. She grieved her lost ability to be useful as she defined it, and nothing I said could convince her she still had value as a person. I learned that words, even deeds, can’t always undo the most personal visions we have of ourselves.

**RK:** Do you have any thoughts about the challenges of bringing medical care and other services together?

**KBW:** In spite of medical advances we have made in the treatment of chronic conditions, we have not made any significant changes in how to organize care. We keep adding options to address problems rather than fully integrating payment for and provision of medical services. So the system keeps getting more complex and costly. Having someone who cares about you is the best insurance possible under these circumstances.

**RK:** What are your thoughts about the challenges of finding paid caregivers? How well does the gray market work?

**KBW:** Finding people who have the right combination of heart, head, and heft is really difficult. As care has gotten more technical, we add training requirements for paid caregivers. Yet we continue to overlook the human dynamic. And costs continue to rise with no clear path to figuring out how to pay for it. I was successful in using the gray market. But the paper is full of stories of it going awry. Having someone who cares about you and stays informed about what is happening is critical no matter who is doing the care.

**RK:** In the family situations you describe, your sisters strived to remain in the community and you helped them. Do you think some tenants who moved into your assisted living buildings did so because it was too hard or too scary to pull off in-home services?

**KBW:** In the end, very few people want to move when they need help. Why would you want to leave your memories, your things, your habits? Undoubtedly my ability to support my sisters professionally, financially, and emotionally made it possible for them to have more choices. Many people make their long-term-care decisions because they have no choices. They are poor or live in rural areas or in states with poorly developed options. But even when there are choices, sometimes people or their families are too overwhelmed to do the things that have to be done to stay where they are.

Keren Brown Wilson, Ph.D., is president of the Jessie F. Richardson Foundation and adjunct professor, Institute on Aging, at Portland State University, Portland, Oregon. She was the founding CEO of the first publicly traded assisted living company in the United States.
Pushing a boulder uphill: that’s what it often feels like when advocating for improvements to long-term-care services and supports in the community at the state level. With seven years as an area agency on aging (AAA) director, twenty-four as the director of the Arkansas Division of Aging and Adult Services, and the last three as the AARP Arkansas Associate State Director for Advocacy, I have found advocating for change challenging, but rewarding.

The bureaucratic maze of state government can grind up anything and anybody.

It’s challenging because of the influence of industry lobbyists and competition for limited resources. It’s even more challenging because the bureaucratic maze of state government can grind up anything and anybody. But it’s also rewarding to see many innovative programs thrive—like Cash and Counseling, the program we began in Arkansas as part of a federal demonstration.

Are You In(side) or Out(side)?
The advantage of advocating from “inside” government is that you’re in the mix of policy and budget decisions. As an agency director I never got everything I asked for, especially on the first ask. However, I was at the table with the governor and state officials who made decisions on budgets and policy.

Advocates can advocate all they want from the outside, but if the state doesn’t submit a Real Choice Systems Change (RCSC) Grant, Money Follows the Person, Balancing Incentive Payment, or Medicaid Waiver application to the federal government, programs will never happen. In Arkansas, several RCSC and foundation grants provided millions of dollars to invest in the planning and development of HCBS services—money that led to affordable assisted living, adult family homes, a sustainable Aging and Disability Resource Center, a robust Options Counseling law (with staff to run it), and the first Medicaid Cash and Counseling project serving consumers. On the other hand, when hiring freezes, budget shortfalls, and politics make life frustrating, outside advocacy can be vital.

For example, in one year, more money was wanted for transportation and home-delivered meals for senior centers. Even though a budget request was made internally, and discussions
occurred within the umbrella department, the request for additional funding never made it into the budget book that appeared on legislators’ desks.

This didn’t stop the aging services network from lobbying legislators. Led by the AAAs, with active involvement from senior centers using their built-in constituency, there wasn’t one legislator unaware of the issue. When it came time to appear before the legislative budget committee, I was grilled by legislators on why I didn’t ask for more money for senior centers and home-delivered meals—didn’t I think senior citizens were deserving? There was a need for more funding, but once the request was denied internally by the department administration, my job was to take the company line.

Budget hearings are the only time I have tap danced in public. In reality, most of the legislators were more than happy to make the administration the bad guy instead of finding money to fund the increase.

A couple of years later, the outside advocates, AAAs, and senior centers again sought money, this time meeting with Governor Bill Clinton to make their case. He suggested they approach the tobacco companies and tell them if they didn’t agree to a tax increase of one cent per pack, the senior coalition would go to the voters and ask for five cents. The tobacco companies didn’t bite. Despite requiring a super majority of 75 percent in both houses of the Arkansas legislature, the AAAs, senior centers, AARP, and older Arkansans went for the one-cent increase.

I could not publicly get out front on the issue, as the tax increase was not part of the executive branch budget package. However, I played an active role behind the scenes and joined the fight. What great fun! The aging network took over the capitol and bested some of the most powerful lobbyists ever to walk Arkansas’ legislative halls. At the session’s conclusion, the statewide newspaper declared “Older People” as Lobbyist of the Year.

The (Oft) Perilous Path to a New Order

As head of the Arkansas Division of Aging and Adult Services, I had the opportunity to serve under four governors, Democratic and Republican. Early on, I realized good politics for older people is good politics for elected officials. It is well documented that elders overwhelmingly prefer to receive care in their home. And they have excellent voting records.

I was fortunate that all four governors supported home- and community-based care. As an insider, I had the resources to bring experts like Dick Ladd to Arkansas. As head of the Division, I was able to apply for RCSC Grants, Money Follows the Person, Medicaid Waivers, and foundation grants (such as Coming Home, from Robert Wood Johnson Foundation) to create affordable assisted living. Without advocates’ support, none of these programs would have been as successful. Consumer advocates put a human face on the issue, have the ability to pressure government employees’ superiors in a way the employees cannot, and can articulate why programs like consumer-directed care are needed.

In contrast, it wasn’t pleasant to go to a legislative hearing, look around the room, and realize you were on your own. Especially when opposition lobbyists had wined and dined committee members the night before. Without outside advocates, life as a bureaucrat can be lonely.

Machiavelli wrote in The Prince, “There is nothing more difficult to take in hand, more perilous to conduct, or more uncertain in its success, than to take the lead in the introduction of a new order of things. For the reformer has enemies in all those who profit by the old order, and only lukewarm defenders in all those who would profit by the new order, this
lukewarmness arising partly from fear of their adversaries...and partly from the incredulity of mankind, who do not truly believe in anything new until they have had actual experience of it” (as quoted in Scott Berkun’s The Myths of Innovation).

**Citizens can trump special interests.**

While it is easy to get providers of services to rally for increases in funding, other issues prove more challenging. Today, the Arkansas HCBS Medicaid waiver funds more home-delivered meals than does the Older Americans Act. But when we were developing the waiver application, some home-delivered meal providers were ambivalent about the waiver because it would require they become Medicaid providers and bill for meals provided instead of receiving a direct grant to run the program. One AAA director opposed submitting the waiver—fearful it would compete with funding they were already receiving. When Arkansas proposed legislation to define and regulate assisted living, the nursing home industry initially defeated it.

Machiavelli’s words ring true today, which is why citizen advocates are critical. They are seen in a different light than paid lobbyists or providers. And there are more of them, so when mobilized effectively, they become a force to be reckoned with. Watching older consumers beat the tobacco lobbyists convinced me that citizens can trump special interests. The little guy can win. But it takes organization, leadership, and resources. This is what brought me to AARP, and I have not been disappointed.

Immediately after I began at AARP Arkansas we were invited to join a coalition to raise the tax on tobacco products during the 2009 legislative session. AARP joined because some of the revenues would support long-term-care services and supports. Advocates formed the coalition, independent from the executive branch. Like the one-cent increase, a 75 percent super majority of both the Arkansas House and Senate was required for passage. This time a 56-cent per pack increase was sought, with additional taxes on other tobacco products. The bill passed without a vote to spare. The Speaker of the House credited AARP Arkansas with ten of the yes votes in the House.

To advance long-term-care services and supports in the community, advocacy is required inside and outside of state government. Rarely will policy advance without both.

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Herb Sanderson, M.P.A., is AARP Arkansas Associate State Director for Advocacy in Little Rock, Arkansas.
Deciding On Care Options in the Digital Age

By Lisa Alecxih and Carrie Blakeway

The advance of the digital age and the advent of new, easily accessible sources of information may rank near the top of the list of the most significant social and cultural transformations since the early 1980s. In the first part of that decade, the personal computer had not yet made its way into most people’s homes. The

Many states maintain Web-based, searchable resource databases with information about available long-term services and supports.

Internet and broadband access did not start to become popular in the workplace until the 1990s, and did not enter people’s homes until the early 2000s. Now, many of us carry a smartphone, which gives almost instant access to the Internet’s vast information resources.

The digital age has been slower to penetrate the world of long-term services and supports (LTSS), primarily because social service agencies and the government rarely lead in adopting technology. But there have been some notable exceptions. In the past decade, the Centers for Medicare & Medicaid Services (CMS) began posting information about nursing homes and Medicare-certified home health agencies on www.medicare.gov, eventually adopting a five-star rating methodology for nursing homes to simplify the complex and technical information. In 2005, the U.S. Department of Health and Human Services launched www.longtermcare.gov as part of the Own Your Future long-term-care campaign to increase public awareness of the need to plan for future long-term-care needs.

Since the early 2000s, several federal and state initiatives have focused on creating “No Wrong Door” or “Single Entry Point” systems, such as Aging and Disability Resource Centers (ADRC), to help individuals with LTSS needs access information and assistance. These initiatives have also helped move the world of LTSS into the digital age, inspiring the creation of new and easier-to-use websites, online planning tools, and robust data-sharing systems that allow partnering organizations to seamlessly share client and resource information. The technology, coupled with telephone and in-person supports, helps meet the needs of a range of individuals who are seeking assistance and making long-term-services decisions.

The ADRC Initiative Makes an Impact

In 2003, the Administration on Aging (AOA) and the CMS partnered to launch...
the national Aging and Disability Resource Center Initiative to encourage states to better integrate their aging and disability services networks and make it easier for older adults and people with disabilities of all ages to access public and private LTSS. Since then, fifty-four states and territories (all except American Samoa and the U.S. Virgin Islands) have received federal ADRC funding, and the program has expanded significantly within states.

As of December 2011, 60 percent of Americans live in an ADRC service area. Initially, states received three-year demonstration grants of approximately $800,000. Over the years, most states have received multiple rounds of continuation funding from federal partners through several AOA and CMS grant programs, and thirty-three states have passed ADRC legislation, developed executive guidance, or contributed state funds to enhance and expand ADRCs. (For more information on grant awards by state, see www.adrc-tae.org; for more information about states’ ADRC-related legislation and funding, see www.adrc-tae.org/tiki-index.php?page=StateLegislation.)

Most ADRCs operate at the community or regional level through partnerships between existing community-based organizations such as area agencies on aging and centers for independent living. Eight states operate their ADRC programs centrally through statewide call centers that provide information, referrals, and assistance with processing of applications for public programs. But these ADRCs often draw on partnerships with community-level organizations to deliver more intensive, in-person services like options counseling and care transitions supports.

**ADRCs Get Creative with Technology**
Charged with the daunting tasks of coordinating and streamlining the fragmented aging and disability service systems, raising public awareness about LTSS options, and helping people access services at a time when demand for support is growing at a rapid rate, many ADRC programs have taken creative approaches that rely extensively on technology.

Thirty-seven states now maintain Web-based, searchable resource databases that provide information about a state’s available LTSS, partly or wholly funded with ADRC funding. These websites are constantly updated and contain educational content, interactive tools, and resource listings useful to people looking for services in their communities, and for long-distance family caregivers looking for services in another state.

Database content varies, but databases usually have listings of all the supports and services people with disabilities of all ages might need—personal assistance, transportation, recreation, and employment supports. They include services offered by providers that serve people in public programs as well as private payers (a significant difference from traditional information-and-referral providers that may not include for-profit services).

Web tools can conduct advanced searches in the database to narrow options by key word, type of assistance, zip code, languages spoken, and hours available. States typically dedicate resource staff at state or local levels to maintain sites. Some sites are more interactive, enabling providers in the community to update their own listings directly, and allowing professionals and information and referral assistance specialists to make electronic referrals to providers listed in the database. Most of these websites also include some kind of benefit screening tool as well as online applications for public programs like Medicaid and State Nutrition Assistance Programs (SNAP).

These databases are frequently linked with sophisticated case management and client-tracking systems that allow client data to be shared securely across multiple service organizations, so information...
Options Counseling and the Personal Touch

Equally (if not more) important than greater access to information through the Internet, ADRCs have also sought to assist people in making decisions about LTSS. Through a service called options counseling, ADRCs support individuals and their families as they weigh choices in the context of their needs, preferences, values, and circumstances. Building upon robust information, referral, and assistance programs, and drawing from both the aging and disability services worlds, options counselors ensure that consumers consider the full range of possibilities when making a decision about long-term supports. Besides helping families respond to immediate crises, they also encourage planning for future needs. Options counseling is often offered in person or by phone, but several states have built dynamic Web-based decision support tools as features of their resource directories.

Building this type of personal and ongoing relationship with individuals is time-consuming and resource intensive. ADRCs draw on a variety of funding sources to cover the cost of providing options counseling, including the following: state funding; Older Americans Act funding; Rehabilitation Services Act funding; State Health Insurance Assistance Program and Medicare Improvement for Patients and Providers Act funding; Medicaid administrative funding; CMS funding for programs operated by ADRCs that provide transition support to people moving back into the community after a hospital, nursing facility, or institutional stay; and, most recently, Veterans Affairs Medical Center funding for options counseling and participant-directed services provided to veterans.

As Mary’s story (below) illustrates, the need individuals have for support with LTSS decision-making is evident. While most older adults would prefer to remain in the community, many end up in a nursing facility simply because they, and the professionals advising them, do not understand the range of options or do not have the time or incentive to investigate and coordinate the supports needed to return home. According to the Agency for Health Care Research and Quality (AHRQ), in 2009, 28 percent of older adults discharged from a hospital went to a nursing facility.

A Definite Need to Know: Mary’s Story

Consider this typical scenario. Mary, a woman in her late sixties, falls in her home and breaks her hip. She is ready for discharge from the hospital after four days. For the discharge planner, a nursing facility appears to be the easiest and safest place to direct her for rehabilitation. Because Mary stayed in the hospital for at least three days, Medicare will cover her short-term stay in a skilled nursing facility. The discharge planner does not know what private-market rehab services are available in the area and is afraid these would take more time to arrange. During her nursing facility stay, Mary becomes disoriented, and despite rehabilitation, she continues to have trouble taking care of herself. Her short-term stay might easily turn into months—even years. At some point, Mary’s financial assets will be spent and Medicaid will begin to pick up the part of the bill her income does not cover.
home or rehabilitation facility (AHRQ, 2009) and more than a third of nursing home residents on any given day were admitted from an acute-care hospital (National Center for Health Statistics, 2006).

The combination of outreach to both professionals and individuals (and their families); an up-to-date, Web-based resource directory that individuals, their families, and their hospital discharge planners can access; and person-centered options counseling offered in the hospital or early on in a nursing home stay can all help to break this cycle. Consumers like Mary can make more informed choices, and states can avoid paying for unnecessary long-term institutional stays.

**Technology and a Place to Call Home**

As outlined in other articles in this issue, during the 1990s a few pioneering states began experimenting with broad outreach strategies and targeted intervention into consumers’ decision-making processes on where to live—in a nursing facility, in community-based residential alternatives, or in one’s own home—particularly among those eligible for Medicaid. In Oregon and Washington, this strategy, along with other LTSS system changes, resulted in being able to serve more individuals under Medicaid, while keeping spending increases in line with (or increasing more slowly than) the rest of the country.

Because of these pioneers’ success and success in other states, Congress, the CMS, and the AOA have adopted information and access for LTSS into their National Balancing Indicators efforts, and for several funding opportunities for states. Also, AARP used measures of access in its 2011 Long-Term Services and Supports Scorecard for states, and concluded that one of the key components in states with the highest level of performance was ease of access. When states enacted public policies designed to establish one point of entry into the system, it made it easier for people to find needed information and to access services (Reinhard et al., 2011).

The next phase in Internet use moves beyond static, searchable information sources to interactive tools that gather information from the user to provide more tailored information and resources. We discuss two examples below.

**Minnesota Long-Term Care Choices Navigator**

(http://longtermcarechoices.minnesotahelp.info/). This is MinnesotaHelp.info’s award-winning tool that provides step-by-step guidance to help older adults and their caregivers figure out what they need to live and age well. It suggests resources in the local commu-

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**Most older adults would prefer to remain in the community, but many end up in a nursing facility because they—and the professionals advising them—don’t understand the range of options.**
United States. The tool also refers users to long-term-care consultation services available in Minnesota to help people make decisions about long-term care. Consultants help people and their families choose services reflecting their needs and preferences (Kane, Boston, and Chilvers, 2007).

**Dartmouth Long-Term Care Decision Aid.** This tool, currently under development, will likely be used in conjunction with the federal website, www.longtermcare.gov. Researchers from the Center for Aging Research and the Center for Informed Choice (both part of the Dartmouth Institute, Dartmouth Medical School), in conjunction with the Lewin Group and the AOA, are developing a Web-based interactive tool focusing on an individual’s preferences and risk tolerance related to long-term care. This tool would help people make decisions and be used by families and professionals. Built upon the Ottawa Decision Support Framework (O'Connor and Jacobsen, 2007), an evidence-based, practical theory used primarily for guiding patients in making medical treatment decisions, this tool will assess an individual’s decision-support needs; provide decision support tailored to his or her needs with the goal of spurring action; and evaluate the decision-making process and outcomes.

The next frontier for technology in decision making may be video. Video could reach individuals in their homes to conduct assessment or counseling sessions with greater human connection than with audio. Smartphone and tablet cameras could show details of how individuals function in their home. Video could also be used to allow individuals to explore lesser-known options, such as high-tech and low-tech assistive technologies, which could make remaining at home more feasible. An important aspect of producing videos to be posted on websites or to be made part of resource databases will be ensuring production quality and the provision of unbiased information.

**Conclusion**

Web tools and other technologies alone cannot provide the type of personalized, in-depth decision support some individuals need when facing what are often difficult, emotional, and life-altering decisions. In-person options counselors must be available to help individuals and their families identify their values, concerns, needs, and preferences and apply these as they consider their options over time. To that end, ADRCs nationwide are engaged in an effort to expand, standardize, and professionalize their options-counseling programs through the development of a national definition of options counseling; the development of standard operating procedures; continuous quality improvement practices; and participation in comprehensive staff training programs in key areas of decision support, cultural competency, and participant-directed and person-centered planning (for more information about the Administration on Aging Options Counseling National Standards initiative, see www.adrc-tae.org).

As we look forward and consider how we will obtain, process, and use information, we need to keep in mind the dramatic changes over just the past decade. Ten years ago, less than 20 percent of adults ages 65 and older used the Internet. In May 2011, 42 percent reported using the Internet. Even more telling is the 74 percent of those ages 50 to 64 who currently use the Internet and the more than 85 percent use rate among those younger than fifty (Pew Research Center, 2011).

Usability testing of at least one federal website that provides long-term-care information suggests that Internet users consider the...
government an objective and trusted source of information because it is not perceived as trying to sell a product. In order to meet the impending wave of demand for information and decision support, and remain relevant to the next generation of people needing long-term services and supports, public agencies must stay current and take advantage of the latest technology and applications. They must also invest and develop the staff that deliver in-person support, as well as the staff that manage and maintain technologies and keep up Web-based tools and databases.

When people are in crisis and searching for answers, out-of-date or incorrect information can be worse than no information at all. The challenge that ADRCs and other entities in the LTSS networks must meet when reaching out to individuals and families is to find the combination of technological and in-person approaches that will successfully transmit useful, timely, well-received, understood—and acted upon—messages.

Lisa Alecxih is a senior vice president at The Lewin Group in Falls Church, Virginia, and director of its Center for Aging and Disability Policy. Carrie Blakeway is a senior consultant at The Lewin Group.

References


Thirty years ago, late-life cognitive impairment was referred to as Organic Brain Syndrome and generally regarded as a normal part of the aging process. People were diagnosed in the disease’s advanced stages, family caregivers were generally told there was nothing that could be done, and families were encouraged to investigate nursing home placement.

Then in 1980 the Alzheimer’s Association came into existence, in part because of the frustration of such caregivers who had no access to home- and community-based services (HCBS), and didn’t want to use nursing homes except as a last resort. There was a general perception that nursing home quality was poor and nursing homes were not Alzheimer’s friendly. In the first fifteen years of the Alzheimer’s Association, advocates put substantial energy into improving nursing homes to serve those with Alzheimer’s Disease, arguing for specialized training, programming, and environments, and helping spearhead the movement toward Alzheimer’s Special Care Units in nursing homes. Later the emphasis in residential care shifted to include assisted living and small family group homes as settings that might work for people with Alzheimer’s Disease.

Most elders with Alzheimer’s or vascular dementia prefer to be cared for at home, so more than 80 percent of dementia care is provided in the community by families—whether blood or fictive. While many family caregivers acknowledge that giving care provides personal satisfaction, it also takes a toll. Family caregivers for people with dementia have higher levels of stress-related hormones, compromised immune function, and high rates of new hypertension (Alzheimer’s Association, 2010).

A study comparing these caregivers to families caring for people with non-dementing conditions found that those who care for people with dementia were more likely to rate the care as emotionally stressful (44 percent versus 26 percent). These caregivers also reported financial hardship (19 percent versus 11 percent), sleep disturbance (32 percent versus 22 percent), and physical strain (24 percent versus 13 percent) (Scharlach et al., 2003). HCBS have been demonstrated to ameliorate some of the strain attached to such caregiving. However, there are multiple barriers preventing easy access to these services.

**Barriers to Using HCBS Supports**

HCBS supports refer to an array of in-home services such as home health, attendant care, housekeeping, and home modification, plus community services such as transportation, daycare,
and support groups. But many families of people with dementia do not seek assistance until the disease is quite advanced or the afflicted person displays challenging behavioral disturbances. And there are emotional barriers to using HCBS, too. Many caregivers are reluctant to entrust the care of a loved one to anyone else. Other barriers are concrete (services may be expensive or inconvenient) or systemic (services may have rigid inclusion criteria or staff lacking knowledge of dementia care).

Exclusion because of dementia
Many people with dementia have been excluded from HCBS programs because of their diagnoses. In California, this population is denied state-funded mental health care. In several states they are denied access to adult day healthcare programs because these diagnoses suggest their conditions are progressive, and rehabilitation is deemed inappropriate. Other states have adopted less restrictive, “habilitative,” criteria for participation; people for whom participation results in maintenance of function are permitted access. However, even this less strict inclusion standard can exclude people with deteriorating dementias.

When admission to programs is based upon functional status rather than diagnostic criteria, people with progressive cognitive impairments may still be denied access. They can be excluded from services because they are capable of completing activities of daily living, even though they cannot perform these tasks without supervision or cueing. With prompting, people with Alzheimer’s Disease may be quite capable of dressing and toileting themselves; however, without this oversight, they would exhibit significant deficits. And, eligibility should take into account an individual’s need for supervision because of poor judgment or behavioral disturbances that could create negative, even catastrophic, outcomes.

Dementia training often inadequate
Without adequate training in dementia care, HCBS staff may be unable to evaluate the afflicted person appropriately or to recommend the right care. When untrained staff evaluate the suitability of a person with dementia for HCBS supports, they commonly do an assessment of functional capacity. People with dementia often retain excellent social skills and can be quite believable. Untrained staff may ask if they are having any challenges with preparing meals or going to the bathroom independently, and will believe the impaired person who claims, quite assertively, that she can manage without help. The accompanying family caregivers may even be viewed by staff as trying to scam the system. Applicants with dementia are then denied services or given insufficient service because of inadequate staff training.

Information and referral staff, benefits counselors, direct-care staff, care managers, and even medical personnel are generally undertrained in dementia care. There is a need for training standards—possibly even certification for HCBS staff—to assure they deliver appropriate care to this population. These personnel would include direct-care workers; nursing staff, social workers, and care managers in community and healthcare settings; transportation providers; information and referral specialists at area agencies on aging, Aging and Disability Resource Centers and other venues; mental health providers; and primary care providers. Without this staff training, people with dementia risk not being accurately identified and evaluated, or given suitable care.

Consumer-directed care should serve both client and caregiver
There is much emphasis placed on providing consumer-directed HCBS programs. Consumer-
directed services (also discussed in this issue by Pamela Doty and others) refer to care organized and supervised by the care recipient. Sometimes with this type of care, the provider is paid directly by the care recipient. This may seem inappropriate for those with significant cognitive impairment, but people with early-stage dementia have opinions about how their care should be managed and their wishes should be regarded. Even as the disease progresses, people with dementia may, in the moment, be able to express preferences. Eventually, family caregivers and others need to serve as surrogates, determining which type of care is in the person's best interests, scheduling that care, and arranging payment to providers.

Some programs not only allow this surrogacy, but may also permit family members to be both surrogate decision-maker and paid care provider. California's In-Home Supportive Services program provides this flexibility. While there is some risk for conflict of interest, for many families it allows the person with dementia to be cared for in a less restrictive home environment as the family caregiver is compensated for care. The caregiver is under less pressure to work outside the home and this may delay or prevent custodial placement.

A related barrier to HCBS use is that of too narrowly defining HCBS beneficiaries. Often, only the needs of the person with dementia are considered. But when support and training are offered to primary caregivers, there can be better outcomes for both. Dementia patient evaluation must include an assessment of the caregiver’s understanding of the condition and social support system. To be effective, the care plan should address caregiver education needs and strategies to strengthen the network of care recipient and caregiver support.

**Integrating HCBS with medical care**
Fewer than 50 percent of people with Alzheimer's Disease ever receive a formal diagnosis documented in their medical charts (Boise et al., 2004). Many physicians experience therapeutic nihilism toward dementing conditions and resist identifying them (Jarvik and Winograd, 1988). Once the disease is identified, little is offered for connection to HCBS.

Several models and tools have been developed to better integrate medical and long-term-care services. The California Guideline for Alzheimer's Disease Management (Segal-Gidan et al., 2011) is a practice guideline for primary care practitioners that makes concrete recommendations for integrating medical care and HCBS care. Several randomized controlled studies have demonstrated the effectiveness of dementia care management offered in conjunction with medical care in improving care quality and decreasing higher-cost hospital and emergency room use (Clark et al., 2004; Vickrey et al., 2006).

Dementia care managers are dementia-trained social workers, nurses, or gerontologists who work with patients and families to assess their needs; deliver education and support; develop a care plan connecting them to medical and HCBS services; and provide follow-up to ensure the plan is working. This role requires specialized training in how to differentiate dementia from depression and delirium; to understand disease progression and symptoms; to understand challenging behaviors like paranoia and hallucinations; to assist family caregivers with management strategies; and to assess caregiver stress. They also need to be well-versed in health and social services that can benefit these families. These professionals function similarly to diabetes health educators, whose services are reimbursed by Medicare, and hopefully, in the future, dementia care management will also be publically reimbursed.

**Cultural and linguistic barriers**
Different cultures have varying views of cognitive impairment and caregiving. To serve people from diverse backgrounds, providers must be linguistically capable and sensitive to the preferred language of patient and family; aware
of cultural mores about decision making (the primary caregiver may not be the person with authority to make care decisions); and aware of the culture’s views about dementia, caregiving, and co-morbid diseases. Basic literacy must also be evaluated carefully, as illiteracy can prevent families from completing paperwork and accessing needed services.

The Continuum of HCBS for People with Dementia
What constitutes a dementia-capable HCBS continuum for people with dementia? How can we maximize the probability that these individuals will remain in the preferred home setting? The continuum resembles that for other disabled adults. However, it has unique features—notably an emphasis on dementia training for all levels of care providers, a focus on surrogate decision-makers, and the need to overcome barriers to condition recognition.

Awareness and outreach
In many communities, especially among less educated groups and less acculturated immigrant groups, dementia is seen as a normal part of aging and families do not seek a diagnosis. Patients don’t receive treatment and

A Diversity Model: Dementia Care Networks

The Dementia Care Network is a model that has been used to develop HCBS for people with dementia and their caregivers in ethnically diverse communities. The network is a collaborative formed among dementia-capable organizations such as the Alzheimer’s Association, and health or social service organizations embedded within a targeted ethnic community.

The collaborative first conducts a needs assessment. As service gaps are identified, the network seeks the resources to fill them through grants to develop service, or training to build capacity within community providers. The first network, El Portal, was convened in 1992 and developed seven support groups, five adult day programs, two legal “clinics,” and two sites where dementia care management was delivered in Spanish or English in a culturally acceptable manner to Latinos in East Los Angeles. Later Dementia Care Networks created services for Latinos in San Diego, Seattle, and other parts of Los Angeles. The model has also been replicated with African Americans and several Asian and Pacific Islander populations.

There were some notable differences found while developing HCBS services for people from different ethnic communities. In Caucasian communities, for example, most support groups might have one or two members from a particular family. In contrast, Los Angeles’ first Spanish-language Alzheimer’s support group meeting was attended by 17 individuals—all members of the same family. In the El Portal Dementia Care Network, Latino families demonstrated repeatedly that multiple family members are engaged in care.

In contrast, it was difficult to get any Japanese caregivers to attend the first Japanese Dementia Care Network support group. When they did, family caregivers were reluctant to speak of their impaired relatives’ behaviors. The disease was highly stigmatized and the behaviors were viewed as shameful. To compensate, the leader, a Japanese social worker, introduced jewelry-making as a group activity. Gradually, as the group worked together and socialized, they began to share concerns. Clearly, peer support and education vary depending upon the targeted ethnic community: providers need to be flexible and adapt to cultural differences.
caregiving is done privately, by the family, with no education or formal supports. For some cultures, dementia is a highly stigmatized condition and family caregivers hide the afflicted person, keeping their condition secret. This is why the continuum of care for people with dementia must include an attempt to break down stigma, educate families, and bring these conditions out of hiding.

**Dementia patient evaluation must include an assessment of the caregiver’s understanding of the condition and social support system.**

Outreach is most effective when conducted by people of the same culture or language group. Gatekeeper programs have also had some success identifying people with dementia. These programs train postal workers, bank tellers, ministers, and similar personnel not only to identify the telltale signs of dysfunction in an older adult with cognitive loss, but also to be supportive, and provide appropriate direction to support services such as care management.

**Information and referral**

Information and referral services providers need specialized training in dementia and about services that may benefit individuals and their caregivers. Staff need to know the providers in the community that are dementia-capable and those that are not. The Alzheimer’s Association’s 24/7 Helpline (800-272-3900) is a specialized resource for this population. Aging and Disability Resource Centers vary in their ability to serve this special-needs population.

**Diagnosis and treatment centers**

To support people with dementia and their families we must first ascertain the probable cause for symptoms of cognitive decline. Federally and state-funded Alzheimer’s Disease Centers can complete evaluations and offer an array of helpful community-based services for people with dementia and their families.

**Benefits of financial and legal planning**

Both early-stage patients and family caregivers benefit from legal and financial planning. This should include an assessment of eligibility for public benefits. The National Council on Aging has an on-line Benefits Check-Up Program (www.benefitscheckup.org) and elder law attorneys to assist with this planning.

**Disease and caregiver education**

An array of educational programs have been developed, and several have been proven through randomized controlled trials to positively impact persons with dementia and family caregivers. The Savvy Caregiver Program is a six-session, psycho-educational class for family caregivers that reduces caregiver burden and depression, and helps them cope with the challenging behaviors of people with dementia (Hepburn et al., 2003). This program is available in a number of states, and is promoted by the Administration on Aging (AOA). Families also can attend disease education and management workshops through the national network of Alzheimer’s Association chapters and other organizations.

**Dementia care management and care consultation**

Perhaps one of the most critical elements of the HCBS continuum for this population is access to a professional trained in dementia and its care, who can work one-on-one with the early-stage patient or family caregivers to assess needs, develop a care plan, provide support and education about the disease and its management, and connect the family to medical, legal, and support services. This service has been shown to facilitate positive outcomes for family caregivers.

Dementia care consultation, a less in-depth level of intervention, is available in the community through the Alzheimer’s Association 24/7 Helpline. Dementia care management is also offered through some healthcare organizations,
area agencies on aging, and their aging service networks. The Elder Care Locator (800-677-1116 or www.eldercare.gov), a service of the AOA, can help with this.

Counseling
As with dementia care management, counselors for people with early-stage dementia and for family caregivers need dementia-specific training. There is individual, couple, group, and family counseling for this population. Counseling people in the early stages of dementia requires a careful assessment of the individual’s capacity for insight, memory, and judgment. One family counseling intervention for spousal caregivers, the NYU Caregiver Intervention, has demonstrated striking outcomes. A randomized controlled study demonstrated that this six-session counseling intervention decreases caregiver depression, helps preserve self-reported health, enhances social support for the caregiver, fosters more benign appraisals of challenging patient behaviors, and, significantly, delays nursing home placement by more than eighteen months (Mittelman et al., 1996). The AOA, through the Alzheimer’s Disease Supportive Services Program, is seeking to make this intervention available nationwide, and broaden its use to adult children and more ethnically diverse families.

Support groups
A wide range of support groups exists for people with early-stage cognitive loss, and for family caregivers to people with moderate to severe dementia. Attendees benefit from mutual support and information sharing.

In-home care
Family caregivers are often time-pressed and emotionally stretched. Many can benefit from in-home services such as respite care, housekeeping, or medical monitoring if the person with dementia has complicating medical conditions. As mentioned previously, some caregivers are reluctant to use these services, and there are other barriers to accessing them. Direct-care workers brought into the home require dementia training. Yet, because they are hourly employees, it’s easier said than done. A program created by the California Southland Chapter of the Alzheimer’s Association targets the family caregiver with training through curricula called, “How to Hire and Train Help in the Home.” Online materials are available at www.alz.org/socal/documents/helpingyou_HowtoHire.pdf.

Wanderer services
Over the course of the disease, an estimated 60 percent of people with Alzheimer’s Disease or a related dementia will become lost and endangered. Identification programs such as MedicAlert, Safe Return, and several GPS-based programs can help keep patients safe.

Adult day services
While marketed to family caregivers as a respite service, adult daycare provides opportunities for social engagement, physical exercise, and cognitive stimulation to the person with moderate and even severe dementia. It may also improve sleep habits. And studies have reported decreased caregiver burden, strain, anger, and depression (Gaugler et al., 2003).

Hospice care
Palliative care at the end of life was not developed with dementia patients in mind, so there are barriers that can delay hospice enrollment for this population. Families and physicians may not recognize the signs of end-stage dementia. Doctors may delay making a referral and be reluctant to certify that the patient has fewer than six months to live. Professionals, including physicians, need more education about end-stage dementia, and about signs of pain and its management in patients with communication challenges. People with dementia often non-verbally communicate distress signals from pain; these can manifest as agitation and combative-ness. Acute illness and medication reactions also
are common culprits that cause the onset of problematic behaviors. A staff well-trained in dementia care can identify these triggers and help resolve them.

For many years, an Alzheimer’s diagnosis could be sufficient to prevent access to hospice services, which are funded largely through Medicare. Because it is more difficult to predict the end of life in people with dementia, some hospice providers were accused of misusing Medicare funding when they delivered end-of-life care to this population. Since then, the industry has developed more accurate assessments for signs that a person with dementia is approaching the last six months of life. Guidelines also are used to score the severity of a patient’s dementia, and medical complications such as multiple hospitalizations, recurrent infections, pressure sores, refusal to eat, or significant weight loss can be used to justify hospice enrollment. Sometimes the tailored care that people with dementia receive in hospice results in their “graduation” (and non-eligibility) from hospice!

**Gatekeeper programs train personnel to identify dysfunction in elders with cognitive loss, and provide appropriate direction to support services.**

Healthcare reform offers practitioners and families an opportunity to realign costs for long-term care. The new Care Transitions Program encourages the development of care management and other community-based services to keep patients from being unnecessarily re-admitted to hospitals. The federal Communities First Program is reimbursing pilot states at a higher rate of match for using community-based Medicaid reimbursable HCBS services rather than nursing homes.

Federal 1115 Medicaid Waiver programs are being used to create integrated services for dually eligible Medicare and Medicaid enrollees, and the Centers for Medicare & Medicaid’s new Center for Innovation is actively soliciting innovative models that reduce medical costs while improving quality of care and health outcomes. These emerging changes in how healthcare and long-term care are bundled and delivered offer opportunities for better integration of HCBS with medical care. Hopefully, the healthcare and long-term-care systems may become less fragmented and more person-centered.

Deciding on the best long-term care to provide for a person with Alzheimer’s or related dementia is not simple. Some people need institutional care because their families live far away, family members are working or exhausted and cannot provide in-home care, or because the dementia’s behavioral manifestations are more personalized and, generally, of higher quality. In a fee-for-service system, individuals and families pay privately for most home and community-based services. In contrast, once an individual has exhausted his or her financial resources, the federal Medicaid system bears the cost of institutional care, but seldom covers community-based care.

**At-Home Care Requires Education and Support**

The availability of a robust and well-trained network of community-based service providers who support family caregivers can help people with dementia remain longer in the preferred home environment. Conversely, a lack of such support can lead to increases in emergency room use, hospitalizations, and institutionalization. People with moderate to severe cognitive impairment cost Medicare three times more than other beneficiaries; this increased cost is driven largely by hospitalizations. People with dementia cost Medicaid nine times more than other enrollees, largely due to nursing home costs (Bynum, 2009).

For families and tax-payers, home-based care is less expensive than institutional care and is
overwhelming. In these cases, residential care can be the best choice and may protect patients from neglect and abuse.

For most people with dementia, however, the home environment remains the preferred care location, offering more personalized care at a lower cost. But to better sustain a loved one at home, families need the support of effective, dementia-knowledgeable home- and community-based services.

Debra L. Cherry, Ph.D., is executive vice president, Alzheimer’s Association, California Southland, in Los Angeles, California. She can be contacted at Debra.cherry@alz.org.

References


Janie, a woman in her mid-fifties, had severe mental illness and used alcohol to self-medicate. She was admitted to a nursing facility from the hospital with serious, chronic physical conditions—cirrhosis, Hepatitis C, and anemia—related to alcohol use. According to facility staff, “alcohol-induced dementia” made it difficult for her to care for herself. It was unlikely Janie would ever leave the facility.

Susan, age 65, was admitted to a nursing facility after she tore apart her apartment during a psychotic episode and broke most of her possessions. She had a host of mental and physical conditions, including bipolar disorder, panic disorder, high blood pressure, high cholesterol, diabetes, neuropathy, and edema. Socially isolated and unable to manage her declining health, Susan faced the prospect of living the rest of her life in a nursing facility.

Janie and Susan are representative of an increasing number of Americans with severe mental illness who live in nursing facilities. The physical consequences of severe mental illness require that we redefine our traditional notions of aging, and re-tool community supports to integrate mental health and substance use treatment into home- and community-based services (HCBS).

Americans with severe mental illnesses, such as schizophrenia, bipolar disorder, and major depressive disorder, live, on average, twenty-five years less than the general population. Individuals with mental illness are more likely to develop chronic medical conditions, including substance use disorders, and become physically debilitated earlier in life (Foti et al., 2006). Those who survive into their sixth decade and beyond face more serious health issues than other Americans of similar age.

Nationally, significant numbers of nursing facility residents have a primary diagnosis of mental illness, with 25 percent being younger than age 65 (Bagchi, Simon, and Verdier, 2009). The implications of this statistic are sobering. Persons with mental illness who could recover and lead productive lives in the community instead are relegated to long-term-care facilities, where they may be cared for but not challenged to regain control of their lives. Older individuals also face an increased “poverty of low expectations” associated with the twin societal prejudices against aging and severe mental illness.

People with mental illness and substance use disorders face significant barriers to relocation.
Criminal justice system records may render them ineligible for help from public housing authorities. Misunderstanding of mental illness and past experience with inadequate community supports can prejudice professionals and family members against an independent living situation. For older people with severe mental illness, additional challenges can include metabolic changes, which affect medication reactions, cognitive issues such as dementia, and increasing physical frailty.

It is time to rethink HCBS to meet both mental and physical needs. It is time for money to follow the whole person. The Texas Money Follows the Person Behavioral Health Pilot (called “the Pilot”) provides one indication of how effective integration might occur.

Texas Rethinks the System
Texas is big—in population, in landmass, and in the size of its Money Follows the Person (MFP) Demonstration. More than 33 percent of Americans leaving nursing facilities under MFP are Texans. Since 2001, when Texas first pioneered MFP as a state initiative, more than 30,000 Texans have returned to the community. Most of these individuals (80 percent) are older than sixty-five. Despite this impressive achievement, people with severe mental illness and substance use disorders have remained more difficult to relocate.

In 2007, when Texas began to develop its Behavioral Health Pilot, more than 7,000 adult Medicaid-funded nursing facility residents in Texas were former clients of the public mental health system. The Texas public mental health system was ranked forty-ninth in funding in the nation (Lutterman et al., 2009), so public sector clients likely represented a subset of total residents with severe mental illness. Texas Medicaid also lacked HCBS services geared toward individuals with psychiatric or substance use disorders. Because Texas Medicaid has strict criteria for admission to a nursing facility, the people in question also had serious medical issues and functional limitations.

The national MFP demonstration, which offers an enhanced Medicaid match and the flexibility to test new services, provided an opportunity to rethink the system. In 2006, the Department of State Health Services, the State’s public behavioral health agency, partnered with the Department of Aging and Disability Services (DADS), which oversees the entire Texas Money Follows the Person Demonstration, and the State’s Medicaid agency to obtain Texas’ Money Follows the Person Demonstration grant, which includes the Pilot.

The Pilot, which started in 2008, integrates mental health and substance abuse services with HCBS. Services began in Bexar County (San Antonio) and, after initial success, spread to adjacent counties and to Travis County (Austin). The Pilot will continue to operate through 2016, at a minimum.

The Pilot targets adults who have lived in nursing facilities for at least three months. Individuals must meet nursing facility medical necessity criteria and have severe mental illness or a behavioral health condition with serious functional impairment. Recovery is the guiding principle—the program doesn’t aim to cure mental illness, but to empower people to take charge of their lives and strive to achieve their full potential. The Pilot was originally intended to target adults younger than sixty-five. To date, however, participants’ ages range from twenty-seven to eighty-nine, with 12 percent of referrals involving those older than sixty-five. One challenge the Pilot has faced is adapting services to older people’s needs and interests.

The Pilot: Nuts and Bolts
The Texas long-term-services system is complex, with lots of moving parts that include the following personnel and entities:
- Department of Aging and Disability Services (DADS)-contracted Relocation Specialists facilitate the overall relocation, including finding housing;
• Medicaid managed care organizations (MCO) develop individual HCBS service plans and coordinate medical with community-based services; and
• Pilot staff, under contract to the state mental health agency, deliver Cognitive Adaptation Training (CAT) and substance abuse treatment interventions.

Partnership is critical. The Pilot staff, the relocation specialist, and MCO service coordinator function as a team to identify Pilot candidates. The team works in the facility and in the person’s residence to prepare for relocation and coordinate supports. Team members also meet weekly by phone before and after discharge to discuss and refine strategies for helping individual Pilot participants achieve their goals. Additionally, Pilot staff members meet monthly with the local MFP resource coordination team to resolve systemic issues, share successes, and plan outreach activities.

One major barrier to relocation has been and remains the lack of affordable, accessible housing integrated into the community. The MFP Pilot partners include local and state housing authorities. Building person-to-person relationships with these authorities has helped the Pilot locate suitable housing, and convince authorities that supports are in place that will make the person a successful tenant. The strong relationship MFP forged with the state housing authority recently resulted in the first-ever dedication of public housing vouchers to relocate residents of state psychiatric facilities.

Learning to Live in the Community
The Pilot services (including CAT and substance abuse treatment), tailored for people relocating from nursing facilities, are available up to six months before discharge (pre-transition), and 365 days after the person returns to the community. An individual transition plan provides continuity with ongoing services after Pilot interventions end.

The program doesn’t aim to cure mental illness, but empowers people to strive for their full potential.

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It can be intimidating for someone who has lived in an institution when they are confronted with the bewildering array of daily decisions most take for granted. Pre-transition services allow a person to develop a relationship with their therapists, actively choose where they will live, identify potential triggers for substance abuse or psychiatric crisis, and develop strategies to avoid relapse.

The University of Texas Health Science Center at San Antonio originally developed CAT in randomized controlled trials with people who had schizophrenia (Velligan, Ritch, and Maples, 2010). The CAT interventions, which are provided by bachelor’s or master’s-level clinicians, function as “adaptive aids” for the brain, helping the person bypass cognitive issues and manage daily life (much as glasses mitigate the effects of poor vision). People identify life goals, and an individually tailored CAT treatment plan is designed to support them. Goals tend to vary by age: older people’s recovery goals can differ significantly from younger people’s goals. For example, younger adults in the Pilot are more likely to name employment as a goal, while people older than sixty-five more often focus on enjoying leisure activities and hobbies.

The CAT service provides simple tools and techniques to help people establish daily routines, organize their living space, and build social skills. These strategies involve objects we all use—signs, alarms, clocks, calendars, checklists, and closet organizers along with training to help the person compensate for the cognitive problems caused by severe mental illness. For example, a person with severe mental illness might get easily distracted from their goal if their surroundings are not well organized. They might put on all of the clothes they see when they open their closet, wearing one shirt on top
of another. The CAT therapist would help them learn to organize their clothes for each day of the week in separate, labeled containers.

Motivating people to become more active and engaged can be a challenge, especially for people who are more advanced in age. Motivational interviewing, a goal-directed counseling technique designed to help people resolve their ambivalence to change, has proved effective. The person learns to develop and update daily events schedules, which helps promote a more active lifestyle.

**Eighty-seven percent of those served have maintained independence in the community.**

Pilot substance abuse services are provided before discharge, in the community and in the person’s home. Services include individual counseling, group therapy, connection to other community programs, and transportation to services. In addition to licensed therapists, a peer specialist who has been through the recovery process provides support. Issues faced include street drug use, alcohol abuse, prescription medication addiction, abuse stemming from treatment for chronic pain, or prescribing practices insensitive to an aging metabolism.

**Whole Person Outcomes**

Janie’s relocation specialist found her an apartment and obtained furniture and household supplies. The CAT therapist helped Janie learn to manage daily tasks such as taking medications, managing money, and keeping medical appointments. The HMO provided medical services, and Janie received individual substance abuse counseling from the Pilot. Janie’s physical health has improved significantly, she takes pride in her independence, and she has begun attending a computer class.

With the help of the MFP team, Susan moved from the nursing facility. She chose to live in a publicly subsidized apartment complex that has supports for people who are aging and those with disabilities. Her goals included achieving mental stability; getting involved in community leisure activities; and focusing on her artwork, which had been very limited in the nursing facility.

**Numbers Point to the Pilot’s Success**

1. The early results of the Pilot are encouraging: out of the 175 persons enrolled in the Pilot, 118 have left nursing facilities for the community. Among those who relocated, 87 percent of the individuals served have successfully maintained independence in the community. Examples of increasing independence include learning to drive a car; obtaining paid employment; volunteering; obtaining a GED; attending exercise or computer classes; and working toward a college degree.

2. Substance abuse services have prevented relapse and helped those who have relapsed regain sobriety. One third of all participants in the Pilot have received substance abuse services (74 percent of those who identified sobriety as a goal have successfully maintained sobriety).

3. People improved on standardized scales, which measure independence in daily life, ability to manage money, medication compliance, and other factors.

4. Average Medicaid expenses for Pilot participants during the first year appeared to be lower than expenses before discharge (DSHS, 2010).
To help reduce her anxiety, Susan and her CAT therapist created a journal in which Susan logs each day’s moods and their causes. They also regularly practiced guided relaxation. Over time, Susan learned to perform relaxation techniques on her own by using an audiotape recorded during previous home visits. The CAT therapist also connected Susan with public transportation services, which she uses for medical appointments and weekly trips to the art co-op. After being provided with a schedule of social events at her apartment, Susan attended a meeting and made a friend. They go to lunch and a movie every other week. She also learned to use health maintenance journals to monitor her blood sugar and blood pressure, and consequently no longer needs skilled nursing services.

Conclusion: The Model Shows Promise for the Future
The goal is systems change. If the Pilot is successful, Texas could include Pilot services among its HCBS alternatives to adult nursing facility care, helping people avoid admission in the first place. In addition, recent changes in federal law allow states to target HCBS services to specific populations, using criteria that are less stringent than they would be at an institutional level of care. It may be possible for states to craft future HCBS supports for people with severe mental illness, which help avert nursing facility admission and better support recovery for those returning to the community.

Whatever the future holds, it is clear that integration of mental health and substance use treatment services with HCBS holds great promise for promoting independence and dignity for people with severe mental illness.

Dena Stoner is senior policy advisor, Department of State Health Services, Austin, Texas. She can be reached at dena.stoner@dshs.state.tx.us. Marc S. Gold, M.S., M.A., is special advisor for Policy and Promoting Independence, Department of Aging and Disability Services, Austin, Texas. He can be reached at marc.gold@dads.state.tx.us.

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As the number of older Americans living with chronic illness and disability grows over the coming decades, the need for focused, effective preventive and acute care will also increase. There are now more than 40 million people in the United States ages 65 years or older, and 37 percent of this group are reported to have severe disability, with 16 percent requiring some type of assistance (Greenberg, 2010).

Most elders want to remain in their own homes to age in place rather than relocate to facilities with on-site nursing and medical personnel, although acute and repeated exacerbations of chronic illness may temporarily require intensive medical monitoring and intervention. Ideally, some or all of this care will be provided at home, preventing institutionalization.

Medical house calls may serve as the main source of primary care for those patients unable to get to the doctor.

The term homecare encompasses an array of home-based services provided by a variety of personnel and funded by many payers. Hands-on personal assistance provided by informal caregivers or paid aides, while essential to keeping functionally impaired older adults at home, is beyond the scope of this discussion. This article instead addresses medically oriented home- and community-based services (HCBS), concentrating on home-visit programs by healthcare providers.

Models of Medical HCBS
Medical house calls are defined as home visits for medical evaluation and management, as part of ongoing primary care, episodic acute care, and post-acute convalescence or rehabilitation. We will outline models, funding, and effectiveness for house calls by physicians, nurse practitioners, or physician assistants, alone or as part of interdisciplinary teams; and we will describe Independence at Home, an important emerging model that synthesizes existing evidence and aims to reduce cost, improve quality, and promote patient-centered care.

Several models exist for medical house calls, with varying levels of effectiveness. Some studies demonstrate increased patient, caregiver, and physician satisfaction, while others show decreased Medicare costs, hospital use, or nursing home placement. Still others show improved satisfaction associated with increased cost. Appropriate targeting, assessment, and follow-up, plus interdisciplinary approaches to medical, functional, and social conditions are
consistently associated with improved processes or patient outcomes (Kao et al., 2009).

Despite differences in types of interventions and evidence, it is useful to break medical house calls into two groups: primary care, which includes transitions to and from acute care; and acute care, or Hospital at Home. These two groups overlap depending upon local circumstances, such as availability of providers and structure of practice, but the general construct provides a framework for understanding the services provided and their potential impact on outcomes.

The primary care model
Medical house calls may complement office visits for older adults with chronic conditions that are hard to manage in the office, or with occasional exacerbations limiting their ability to get to scheduled office visits. Or they may serve as the main source of primary care for patients unable to attend appointments because of physical, cognitive, or psychiatric impairment. A landmark study of 1993 Medicare claims data said most house calls are made by primary care physicians (internists, family practitioners, general practitioners, and geriatricians), with only 8 percent attributed to physicians in other specialties (Meyer and Gibbons, 1997).

Although house calls still represent less than 1 percent of all outpatient medical services billed to Medicare, the number of these visits has increased steadily over the past decade. More recently, a review of Medicare data from 1998 to 2003 showed that the total number of house calls increased by 43 percent, with more than 50 percent of these visits made by primary care physicians (Landers et al., 2005).

By definition, medical house-call programs include at least one medical provider such as a physician, nurse practitioner, or physician assistant. At one end of this medical provider-based practice spectrum is the solo private practitioner who occasionally makes a house call—typically to a patient at the end of life with whom he or she has a long-standing relationship—to manage symptoms or provide emotional support. At the other end is the large multistate corporation, which has hundreds of individual house-call providers and integrated laboratory or radiology services. The capacity of such house-call programs depends upon staffing, geography, and population density.

Although the medical literature of the past thirty years is peppered with occasional essays or reports describing physician or patient satisfaction with individual house calls, there is a relative dearth of data on the effectiveness of either lone practitioner visits or large corporation programs. Evidence for the large practice model exists in business literature, which chronicles the growth of this model as an industry.

For example, Care Level Management provided medical house calls and care coordination in consultation with patients’ primary care providers as part of a Medicare demonstration project targeting high-cost beneficiaries from 2001 to 2007. In 2008, it was acquired by Inspiris LLC to augment Inspiris’ medical care and care management services for high-cost Medicare and Medicaid patients. Reports from Inspiris, which focuses on physician house-call services for Medicare and Medicare Advantage patients, show that hospital admissions, re-admissions, emergency department visits, skilled nursing facility days, prescription medications per patient, and total costs are significantly reduced by their services, while patient satisfaction and health-plan margins increase.

One internal study of 400 “special needs plan” patients (those having chronic disease, functional disability, and high expenditures) and 400 matched controls demonstrated a 63 percent reduction in Medicare hospital admissions in the first seven months, prompting the plan to terminate the study and apply the Inspiris care model to all 800 patients. This success led to Inspiris’ recent acquisition by United Health Care, a branch of the largest health insurance company in
the United States (Coleman, 2011a; Coleman, 2011b; Inspiris LLC, n.d.).

The teaching hospital model
Academic house-call practices subsidized by hospitals with teaching programs typically fall somewhere between the two ends of the spectrum described above, with a small cadre of faculty dedicated to educating learners, while providing patient care to a limited panel of patients in the hospital’s immediate geographic area.

A striking exception is the Visiting Doctors Program at the Mount Sinai School of Medicine in Manhattan, with fourteen physicians, four social workers, and four nurses serving more than a thousand patients annually. This thriving group has published data describing their program’s financial contribution to the sponsoring hospital through in-patient admissions and outpatient visits, although the fiscal impact on the healthcare system beyond the hospital is not addressed.

Nursing and social work services are funded through the program budget and are not reimbursted by Medicare. Although direct billing for medical home visits covers only about 24 percent of the program’s cost, the remainder is supported by philanthropy (8 percent), the affiliated medical school (10 percent), and the hospital (58 percent) (Desai, Smith, and Boal, 2008).

The interdisciplinary team model
As noted above, targeting high-cost, frail older patients who would likely otherwise transition frequently between acute-care hospitals and post-acute facilities is key to the financial sustainability of house-call practices. Another important component of many successful models is an integrated interdisciplinary team that can simultaneously address medical, functional, and social problems. Interdisciplinary teams of medical providers, social workers, pharmacists, therapists, and other professionals have long provided medical house calls and home-based primary care (HBPC) through the Veterans Administration (VA) health system.

The unique federal funding of VA HBPC makes it difficult to compare its results to fee-for-service or capitated health systems. But studies of HBPC demonstrate improved health-related quality of life and satisfaction among patients and caregivers, reduced length of hospital or nursing home stays, and, as expected, increased outpatient visits and homecare visits, with a 24 percent reduction in total VA costs for HBPC patients (Edes and Kendall, 2005). Among veterans in HBPC who were also Medicare patients, combined VA plus Medicare hospital admissions were reduced 25 percent, and hospital days were reduced 36 percent.

Enrollment in VA HBPC was associated with a net reduction of 10.2 percent in Medicare costs, and a net total reduction of 13.4 percent in combined VA plus Medicare costs, after accounting for the added costs of the HBPC intervention (Kinosian and Edes, 2010). However, these results may not fully apply to settings outside the VA, because funding mechanisms are substantially different for the VA compared with Medicare or commercial insurance. And all team members, including medical providers, are salaried by the VA.

Community collaboration models
Other notable models of team-based house-call practice rely on mutually beneficial collaboration with community partners. For example, a Philadelphia program named EPAC (Elder Partnership for All-Inclusive Care) pairs a medical house-calls practice (that uses a physician and nurse practitioner duo) with the local, community-based long-term-care provider and the area agency on aging. It coordinates medical care, social work, informal caregiving, and paid

Successful house-call models use an integrated interdisciplinary team that can address medical, functional, and social problems.
services such as transportation, medical equipment, home health aides, and adult medical daycare for dually eligible patients. When compared with Medicaid waiver HCBS control patients, EPAC patients had 23 percent lower Medicaid costs largely from 76 percent fewer nursing home months over the span of five years (Kinosian et al., 2011).

Another innovative approach to team-based house calls is the Geriatric Resources for the Assessment and Care of Elders (GRACE) program at Indiana University. In this model, a geriatrics nurse practitioner and social worker make house calls and collaborate with an office-based primary care physician and geriatrics interdisciplinary team to provide integrated home-based care management. GRACE patients showed a reduced rate of emergency department visits and hospital admissions. Costs outside the health system were not evaluated, including home healthcare, durable medical equipment, nursing home care, and existing community-based interventions, such as exercise groups. In this high-risk group, additional analyses demonstrate a net cost neutrality over two years of intervention, followed by net decreases in the year following the intervention, suggesting that intensive primary-care interventions targeted to high-cost patients improve quality and satisfaction without increasing cost to the health system (Counsell et al., 2007; Counsell et al., 2009).

Hospital at Home
A logical extension of providing primary care house calls, when the medical need arises, is providing acute hospital-level care in the home. This is the Hospital at Home (HaH) model of care. The main rationale for HaH care is that the traditional acute hospital environment is unsafe for many patients and unnecessarily expensive. The seminal 2000 report from the Institute of Medicine (IOM), To Err is Human, Building a Safer Health Care System, highlighted the notion that healthcare quality and patient safety are significant concerns in the hospital (Kohn, Corrigan, and Donaldson, 2000).

Iatrogenic events occur commonly in the hospital. The IOM estimated that at least 44,000 people die in U.S. hospitals each year from medical mistakes, at a cost of between $37 and $50 billion. Older adults commonly experience debilitating complications such as delirium, functional decline, pressure sores, and nosocomial infections. Hospital discharge and the transition from hospital to home are especially fraught with difficulties, as evidenced by the remarkably high rates of hospital re-admission among Medicare beneficiaries.

Hospital at Home provides services, therapies, and technologies usually associated with acute inpatient care, but in the home setting. There are a variety of such care models—this article focuses on those substituting for inpatient hospital admission. These models treat acute conditions in the home, providing treatment that requires hospital-type technologies or hospital-level care; substantial physician and nurse input with full-time clinical coverage; care coordinated in a way similar to an inpatient hospital ward; and ancillary pharmaceutical, laboratory, and basic radiology services.

A wide range of conditions has been treated in HaH, all of which occur often and account for a significant proportion of hospitalizations. These conditions can be diagnosed in a straightforward manner and treated safely, efficiently, and effectively in the home. Such conditions include community-acquired pneumonia, exacerbations of chronic obstructive pulmonary disease or congestive heart failure, cellulitis, deep venous thrombosis, pulmonary embolism, volume depletion, dehydration, urinary tract infection, and urosepsis, among others. In these models, eligible patients are identified in the hospital emergency department and offered the option of HaH care.

There have been a number of well-conducted studies of substitutive HaH reported in the literature. Many have been randomized con-
trolled trials conducted in countries with single-payer systems. In such systems, the economic incentives to provide HaH care are aligned. A recent Cochrane meta-analysis examined ten randomized controlled trials of substitutive HaH care and found that patients receiving HaH care reported higher satisfaction with care than those receiving inpatient care, and that HaH care was less expensive than traditional acute inpatient care. Remarkably, there was a 38 percent reduction in the risk of death at six months for HaH patients compared with traditional acute inpatients (Shepperd et al., 2009).

There was a 38 percent reduction in the risk of death at six months for Hospital at Home patients, compared with traditional acute inpatients.

In the United States, investigators at Johns Hopkins led the work on HaH, and developed a substitutive HaH model with a robust physician component. The research model focused on treating patients with pneumonia, chronic heart failure, chronic obstructive pulmonary disease, and cellulitis. A national multisite study of the Hopkins model was conducted in Medicare managed care and the VA health systems and demonstrated that HaH care was feasible and efficacious, providing hospital-level care at home that met standard disease-specific quality metrics.

Compared with patients treated in the acute hospital, those treated in HaH suffered fewer clinical complications, including use of sedative medication, chemical restraints, and incident delirium. Patient and family member satisfaction was higher. Although patients were not required to have a caregiver (30 percent lived alone), caregiver stress was lower. The HaH patients improved in the ability to perform instrumental activities of daily living compared with usual care patients. And the average amount paid for HaH patients was lower, the savings resulting from reduced use of laboratory and high-tech procedures (Leff et al., 2005).

Over the past several years, the Hopkins group has focused on disseminating HaH into the U.S. healthcare system. Several additional VA medical centers have adopted the model, as has Presbyterian Health Systems in Albuquerque, New Mexico, an integrated delivery system that uses HaH for Medicare Advantage patients. Most recently, the commercial entity Clinically Home has developed and piloted a more scalable version of the Hopkins HaH model. This model provides physician visits via two-way, biometrically enhanced telemedicine visits, with nurse practitioners and nurses making visits in the home, admitting patients for a thirty-five-day admission so as to better manage the post-acute transition, and a systematic approach to reducing variations in care.

Unfortunately, there are substantial payment barriers in fee-for-service Medicare. Recent initiatives such as bundled payments demonstration programs promulgated by the Centers for Medicare & Medicaid Services (CMS) Innovation Center may help reduce such barriers to HaH implementation in Medicare.

Independence at Home: Culmination of the Evidence

Finally, an important emerging model of medical house calls incorporates the key principles of timely and responsive, patient-centered care targeted at high-cost users to reduce costs while increasing quality and satisfaction. These principles, as demonstrated in the studies and successful practices noted above, culminated in the Independence at Home (IAH) Act, section 3024 of the Patient Protection and Affordable Care Act of 2010. The IAH Act mandates that CMS perform a demonstration study of the medical house-call model with a novel payment methodology representing a major shift from standard Medicare reimbursement.

The target population for the IAH demonstration is the most frail, medically complex
older adults that constitute the highest cost segment of the Medicare population. Financial incentives are redirected from office-based specialists to mobile teams that must demonstrate improved outcomes for these patients, coordinating care across different settings, including hospitals and nursing homes. Each multi-disciplinary team of medical providers, social workers, and office support staff works closely with existing community providers of pharmacy, medical equipment, home nursing, rehabilitation, home health aides, and hospice to organize and deliver appropriate care and supplies to patients when and where they need them. Effective, reliable technology promoting efficient communication of critical health information among providers and facilities is an essential part of the IAH team’s infrastructure, as is around-the-clock access to skilled telephone triage and urgent visits (as needed) to prevent unnecessary trips to the emergency room and hospital admissions.

In the current political and fiscal climate, many entities could benefit by sponsoring IAH teams, including hospitals, health plans, physician groups, homecare agencies, long-term-care facilities, and accountable care organizations. Individual physicians, nurse practitioners, or multi-disciplinary teams with experience providing in-home primary care to patients with multiple chronic illnesses may participate in the IAH demonstration. Individual practices may also form a geographic consortium to participate in IAH as a single entity. Each participating practice or entity must provide services to an average of at least 200 eligible beneficiaries during each year of the demonstration, and must be available daily and around the clock to provide care. They must also utilize electronic health information systems, mobile medical technology, and remote monitoring systems. They are required to provide data on multiple quality measures, and in return will receive incentive payments and share in Medicare savings. Complete details of practice and beneficiary eligibility criteria are beyond the scope of this review, but are available on the CMS website (www.cms.gov/DemoProjectsEvalRpts/downloads/IAH_FactSheet.pdf).

The IAH teams will provide coordinated, home-based care to Medicare beneficiaries with multiple chronic illnesses, functional disability, and demonstrated high healthcare costs; show a minimum of 5 percent annual savings for Medicare, compared with predicted costs for the target population; share in savings with Medicare (beyond this first 5 percent) to use for program development, including technology or other clinical services; meet three minimum performance standards (patient and family satisfaction, good clinical outcomes, and the aforesaid 5 percent savings); preserve existing Medicare coverage; and be completely voluntary.

The “shared savings” payment model limits the financial risk to Medicare, and gives providers motivation to select high-cost patients who have the greatest potential for savings. At the same time, these highly skilled interdisciplinary teams will provide our neediest, most medically vulnerable patients with safe, effective, high-quality, and timely care centered on the patient at home (DeJonge, Taler, and Boling, 2009).

Medical House Calls: An Alternative to Current Practice

Economists, scientists, and policy makers generally agree that the current hospital-centered healthcare delivery and payment system is not sustainable in the face of the burgeoning population of older adults with chronic complex multimorbidity. Medical house calls, including hospital-level care at home, are an essential component of primary and acute care for these patients, and have been shown to improve outcomes and decrease costs. Fortunately, these patients are the most likely to benefit from intensive outpatient management and coordination of care over time, performed by experienced interdisciplinary teams versed in geriatric principles and practice. These home-based,
Medical primary-care programs are only rarely well integrated with existing HCBS (as in the case of the EPAC model), and otherwise depend on institutional investment or private payment arrangements. Future research, including evaluation of the IAH demonstration project, should identify more effective practices that may be replicable on a national level.

Jennifer Hayashi, M.D., is assistant professor of medicine at Johns Hopkins University School of Medicine in Baltimore, Maryland. Bruce Leff, M.D., is professor of medicine at Johns Hopkins University School of Medicine.

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Note from the Authors

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Caring for the Caregivers: Developing Models that Work

Developing an effective set of caregiver supports is a key strategic approach to helping people who need long-term services and supports in the community.

Programs and initiatives supporting informal caregivers have been a part of the older adult services spectrum for several decades. More recently, such supports have been extended to serve younger persons with disabilities. Applied research on caregiving—including a major survey in 1980 of more than 600 family caregivers, initiated by the Benjamin Rose Institute on Aging (BRIA) with funding from the Administration on Aging (AOA)—led to ideas for program development across the country.

The 1980 study (Noelker and Wallace, 1985) served as the basis for the ongoing development of caregiver services and research projects BRIA has carried out across the last thirty years. Findings from the study’s interviews with a deliberately diverse sample of caregivers in Ohio and western Pennsylvania uncovered the variety of burdens caregivers faced, plus their need for respite, education, training, and other interventions. These and other research efforts also led to the Family Caregiver Alliance in California and the Family Caregiver Support Program in Pennsylvania, and culminated in the passage of the Family Caregiver Support Program in 2000 under Title III of the Older Americans Act.

Most research, advocacy, and policy work has emphasized the benefits of respite for the caregiver—frequently in the form of stress relief and reduction, or management of feelings of burden. But respite typically has benefits for the care receiver as well, such as opportunities to socialize and form new relationships.

Respite is a vital support service for caregivers, although no one agrees on its definition. Some use the term to describe the purpose of a support service; others use it to describe the service itself. In any case, respite care implies someone is being relieved of caregiving responsibilities on a temporary or periodic basis. Such relief enables caregivers to sustain their caregiving, and care receivers to continue living at home with home- and community-based services (HCBS).

Services for Caregivers

Case managers at BRIA have been attentive to the needs of family caregivers since the 1960s, when research documented the benefits of supports for spouses and other relatives following client discharge from the hospital. Respite service, however, was formally instituted at BRIA in 1986, when state funding allowed the establishment of the Adult Day Program targeting the service to African American caregivers. The program is now one of

By Linda Noelker and Richard Browdie
several services caregivers can access for respite, along with in-home and Senior Companion services. Having this suite of services for respite purposes readily available from one source enables case managers to accommodate the varied and changing needs of caregivers and clients.

Mr. P’s story (below) illustrates how the combined use of the Adult Day Program and in-home Senior Companion services provides socialization and other benefits to his mother, while he uses time off from caregiving to attend to his needs and other responsibilities.

In contrast, the caregiving trajectory for Ms. S (page 105) has been a long one, with family crises and a life-threatening illness requiring progressively more extensive use of varied types of supportive services. Both caregivers recognized early on that they needed to reach out for assistance if they were to continue working and caregiving without compromising their health and well-being.

Unfortunately, BRIA case managers know from experience that many caregivers, unlike Mr. P and Ms. S, are reluctant to relinquish their relative’s care to others, even temporarily. Clients often struggle with complex emotions such as feelings of guilt and abandonment; this impedes their ability to accept support services or use them effectively. BRIA case managers recognize this difficulty and know that caregivers can benefit from a thorough assessment and counseling, which enables them to identify appropriate services and educate caregivers on how to best use them. BRIA case managers have conducted this process individually with the primary caregiver and with other family members to help organize the family unit’s caregiving efforts. The purpose is to avoid delayed or insufficient use of respite services and prevent their effectiveness from being compromised.

But there is a lack of consensus in the field about when respite services should be initiated and how much, how often, and for how long respite should be used to maximize its benefits. Further complicating the situation, the disparate meanings respite has taken on over the years challenge even professionals in the field to use a consistent definition.

As a result, case managers and other BRIA staff have labored for more than two decades to broaden and refine the agency’s approach to supportive services for caregivers in ways that improve their availability, quality, and effectiveness. The agency’s extensive and long-standing research program on family caregiving has yielded findings that led to the development and use of an assessment form for family caregivers that helps identify sources of strain, burden, and needs for assistance.

Respite Services Complement HCBS

Mr. P brought his 82-year-old mother from Alabama to live with him and his wife when a visit had indicated her Alzheimer’s Disease was too advanced to allow her to live alone. His family physician referred them to BRIA and the Alzheimer’s Association’s local chapter, urging them to get assistance in managing the stress of what was likely to be a long and difficult caregiving process.

Mr. and Mrs. P rearranged their work schedules, with Mr. P switching to an evening shift because his mother could not be left alone. A combination of HCBS supply Mr. P with respite and his mother with meals, socialization, and case management. While his mother attends BRIA’s Adult Day Program two days a week, and has an in-home Senior Companion two other days, Mr. P is free to catch up on sleep or do errands and handle household projects. Half of the Adult Day Program costs are covered by the local area agency on aging under National Family Caregiver Support Program funding, while the rest is paid out of pocket.
Respite Enables a Parent to Remain at Home

Ms. S is single, employed, and the caregiver for her mother, who has Alzheimer’s Disease and lives with her. Her mother is enrolled in Ohio’s PASSPORT waiver program, and Ms. S initially used the BRIA Adult Day Program for respite. As her mother’s disabilities increased because of a serious fall, home-care services were substituted to provide her with personal care, meals, and supervision, and to provide Ms. S with respite. When her elderly aunt in Florida died, Ms. S used residential respite to attend the funeral. Then Ms. S increased her use of both in-home and residential respite when she began cancer treatments. The combination of respite and waiver services has enabled Ms. S to care for her mother at home for more than ten years, despite the many challenges.

Caregiving Award (which recognizes and celebrates caregivers’ ingenuity in making the care process easier, safer, more comfortable, and of better quality) was presented to three family caregivers for the creative devices they invented to improve caregiving (for more information, see http://www.benrose.org/InnovationAward/ICA_2011_Winners.cfm).

These efforts to advance supportive services for caregivers have required BRIA’s close collaboration with other nonprofit and for-profit service organizations, public agencies, educational institutions, and professional associations at the local, state, and national levels. Although significant progress has been made over the decades, support services for caregivers continue to be underfunded, and their value will be challenged in funding debates about priority programs and services. For these reasons, BRIA’s advocacy role will expand as needed to ensure that respite and other services for caregivers receive necessary support.

Challenges Drive Programs and Policy

In the public policy arena, support for informal caregivers springs from two important and related challenges they face. The first involves the well-documented burdens and strains that significantly impact the caregiver: from adverse effects on employment and changes in health, to family conflict and dysfunction, the effort to support a loved one can be harmful in the best of circumstances—and devastating in the worst. Thus, there is a public interest, even obligation, in offering help to people who undertake these difficult responsibilities.

The second challenge revolves around caregivers’ unpaid efforts (estimated at $375 billion in 2007), which frequently relieve the public of significant financial outlay, strengthening public interest. The most constructive way to view this is that there is a partnership between the caregiver and the agencies that are in a position to help, especially if they are publicly funded. As such, there should be some effort to make the approaches to this partnership as effective and widely avail-
Many caregivers are reluctant to relinquish their relative’s care to others, even temporarily.

In both Mr. P’s and Ms. S’s stories, the continuity and flexibility of the supports offered was made possible by a combination of public programs (Ohio’s Medicaid Waiver and the AOA-funded Family Caregiver Support Program, or FCSP) and private philanthropy (The Benjamin Rose Trust). But FCSP resources are limited, so not all caregivers have access to them. Even when they are available, FCSP resources may be insufficient.

But BRIA is willing to use its resources in this fashion for the elders and families it serves. The larger issue, however, is that an effective public policy to support informal caregivers cannot be successful if it asks families and committed caregivers to rely on an uncertain or unpredictable combination of agencies, plus philanthropy.

While a state-by-state comparison on this issue would require extensive analysis for definitive results, there are states where public support is more consistent. In some cases, family caregiver assessment and preferences are incorporated into the care planning process in publicly financed and sponsored systems, as it has been at BRIA.

Research by such agencies as BRIA indicates that for the long term, it is important and effective to use a flexible yet actively caregiver-sensitive approach. The development of an effective set of supports for caregivers is a key strategic approach to support those needing long-term services and supports in the community.

The work by states funded under the 2006 Lifespan Respite Care Act to address the accessibility and affordability of respite care for families possibly will advance efforts to make evidence-based and cost-effective respite care more widely available. However, initial funding for this program was limited ($2.5 million in 2009) and remains insufficient to address the magnitude of need.

Conclusion
Until publically funded HCBS programs define the family unit as the client, and integrate services for family members involved in caregiving with those for the older and perhaps disabled person, it is unlikely that family caregivers’ needs will be adequately met.

As previously mentioned, there are precedents for effectively coordinating caregiver support systems with supports for persons with direct-care needs. Beyond the practices of a few leading agencies, there are systems where the needs of caregivers and consumers are assessed as an integrated, holistic picture that illustrates the spectrum of necessary caregiver and family supports.

What we need is leadership in program policy, which could drive implementation at the national and state levels. This could have a significant impact on forging the important link so necessary to developing a truly comprehensive and person-centered national approach to long-term services and supports in the community.

Linda Noelker, Ph.D., is senior vice president of planning and organizational resources, and director of the Katz Policy Institute, at the Benjamin Rose Institute on Aging, Cleveland, Ohio. She is also an adjunct full professor of sociology at Case Western Reserve University, Cleveland. Richard Browdie is president and CEO of the Benjamin Rose Institute on Aging.

References
The first homecare program in the state of Washington began as a state-funded add-on to a client’s cash grant for public assistance. Instituted in the late 1960s, this program determined if a client needed assistance in the home, and authorized payment after services were delivered. The client had to recruit, hire, and supervise a worker, pay the provider and submit taxes to the federal government, plus submit a bill for provided services to the state. State dollars funded the program, but provided no assistance to the client with locating workers, or other employer responsibilities.

Most of the program’s potential clients were elders, who often found employer responsibilities cumbersome. Even though they were authorized for the service, many never found a worker or were unable or unwilling to take on employer responsibilities. The program was somewhat similar to today’s consumer-directed approaches, but did not share in their success.

In the 1970s, the Chore Services Program (household and personal care tasks) was redesigned and added homecare agencies to the service-delivery model. This allowed clients to choose between an individual provider program or an agency provider, which made the program more accessible, especially to older people, and the caseload doubled. Funding mainly came from the state general fund and limited federal Social Services Block Grant funds. Hours were authorized after assessing the client’s ability to perform activities of daily living and instrumental activities of daily living with the Client Review Questionnaire.

Federal Funding for Homecare Services
In 1981, Washington State had a significant budget deficit. The Department of Social and Health Services budget process emphasized institutional services funding, reducing primarily state-funded community services. The legislature decided to reduce the Chore Services Program by about 4,000 people. Consumers needing the fewest hours were terminated from the program and no longer eligible for services. Clients who lost services were followed for about nine months to determine their outcome without service. Then the funding dried up for continuing the study. The findings were not statistically significant, but clients used emergency rooms and hospitals more frequently, and were dying at a higher rate than those who remained on the program.

After this major cutback in the Chore Services Program, consumers and advocacy groups continued to pressure the governor, the legislature, and policy makers in the Department of
Social and Health Services to find a way to fund homecare, the consumer choice for meeting long-term-care needs. In 1984, the Department implemented a 1915(c) federal waiver (Community Options Program Entry System) and offered homecare and residential services as community-based options for clients.

Additional federal financing opportunities were explored and, in 1989, the legislature approved the request for adding the Medicaid Personal Care State Plan option. This program was available to low-income (categorically needy) older people, and people with physical, mental, and developmental disabilities. The Department of Social and Health Services continued offering a choice between an individual provider selected by the consumer and the agency program under the federal programs. Agencies participating in the homecare program now had to be licensed. Under the individual provider program consumers could select relatives as their providers. Allowing family members to be providers helped in finding workers, especially when the economy was robust and in-home workers were difficult to recruit. More than 64 percent of the providers today are relatives of consumers.

Opportunities to meet the needs of consumers in the community increased because of the federal financing with the Home- and Community-Based Waiver program. Expanding in-home services became a major factor in “balancing” the Washington State long-term-care system of services. More than 60 percent of the long-term-care caseload in Washington is now served at home.

The SEIU Gets Involved
In 2001, the Service Employee International Union (SEIU) decided to organize homecare workers in Washington. The SEIU had been active in a few other states in long-term care, especially in nursing homes, but they decided to organize Washington's homecare workers because the state's system had one of the largest homecare components in the country, and it operated statewide. Washington State was also viewed by the SEIU as having one of the most balanced long-term-care systems in the United States, which the SEIU wanted to see replicated in other states.

The SEIU began their work in Washington by proposing a citizen initiative to improve the quality of in-home care services provided by homecare workers (also referred to as individual providers or IPs) through better regulations, higher standards, increased accountability, and giving consumers a better chance of obtaining services. The initiative also aimed to create a Homecare Quality Authority and encourage stability in the in-home care workforce through better training and collective bargaining. In November 2001, Washington voters passed RCW 74.39A.220 by a large margin.

The Homecare Quality Authority (HCQA) became a Washington State government agency governed by a nine-member board consisting primarily of former and current consumers of in-home care services, including representatives from the Developmental Disabilities Council, the Governor’s Committee on Disability Issues and Employment, the State Council on Aging, and the Washington State Association of Area Agencies on Aging. Governor Locke appointed Charles Reed, former Assistant Secretary of the Washington State Aging and Adult Services Administration, to serve as chair. In May 2002, Governor Locke appointed the rest of the nine-member volunteer board. In 2003, Mindy Schaffner was appointed the first executive director of the HCQA. Rick Hall succeeded her in 2006 and served in the position until the HCQA was dissolved in 2010.

Building a Bargain: A Seven-Year Timeline
The organization of the HCQA became the vehicle through which homecare workers formed a union. In 2002, homecare workers formed a bargaining unit and SEIU Healthcare 775NW was elected to represent the approximately 25,000 workers in collective bargaining.
In summer 2002, the HCQA and SEIU began the bargaining process, and in October, HCQA and SEIU reached consensus on a collective bargaining agreement (CBA) to be submitted to the legislature for approval. The initiative that created the HCQA and provided for the organization of homecare workers gave authority to the HCQA to act as employer for homecare workers in order to bargain for wages and working conditions, but not for hiring and firing of homecare workers: this would be the responsibility of the individual consumers of in-home services. The HCQA's role would be to represent Washington State in bargaining with homecare workers. The new state law created by the initiative decreed that once the CBA was reached, the governor would pass it on to the legislature for consideration. The legislature could only accept or reject the CBA; they did not have the authority to change the agreement.

In spring 2003, the legislature rejected funding for the CBA. The parties subsequently completed negotiations over a new one later in October. That same fall, HCQA conducted a feasibility study for a Referral Registry to match those in need of in-home services with workers who could provide the service.

In early 2004, the legislature approved funding for the first ever CBA. This agreement called for increasing the hourly rate for homecare workers to $8.93, established workers' compensation coverage, and provided healthcare for those who work at least 86 hours per month through a Taft-Hartley Trust to be created by the bargaining parties.

Also in 2004, the legislature made several significant changes to the statute under which the HCQA was created. One principal change provided that the governor, rather than HCQA, would be the public employer of homecare workers solely for the purpose of collective bargaining. This brought the homecare workers' bargaining statute more closely in line with other Washington state collective bargaining laws. The HCQA's continued role was to provide consultation during bargaining and to communicate issues relating to in-home care services received by consumers.

The HCQA also continued to be responsible for implementing some provisions of the collective bargaining agreement—most notably the newly required IP Workers' Compensation Program, and creating the Taft-Hartley Trust to provide healthcare for eligible homecare workers.

Also in 2004, the legislature provided funding for HCQA to develop and test an accessible Referral Registry database. The registry is a customized Internet-based system designed to match the needs of publicly funded in-home consumers with pre-qualified homecare providers. Participation in the registry is voluntary and not a condition to receive or provide Medicaid services. The registry provides Medicaid-eligible consumers with a referral, listing the names of screened providers. Upon receiving the list, the consumer is responsible for calling, interviewing, and selecting their provider. Registry contractors provide training to consumers and their families for the purpose of interviewing and selecting providers. The consumer’s case manager approves final authorization of services. Worker applicants must be at least eighteen years old, and successfully complete a background check, face-to-face interview, and an introductory course before being listed on a consumer referral.

Also that year, HCQA was awarded a $1.4 million demonstration grant from the Centers for Medicare & Medicaid Services to implement a pilot of four homecare Referral Registry sites (serving nine counties) using the Referral Registry database. The immediate success of these demonstration sites created a demand for these services statewide.
In 2005, the legislature approved funding to expand Referral Registry services to cover the entire state. It also approved funding for a new CBA covering the 2005–2007 biennium. This new labor agreement increased the hourly rate to $9.20, provided for dental and vision insurance, mandated federal tax withholding, gave workers paid time off, and brought Washington State’s contribution for homecare workers’ healthcare to $480 per month.

In 2006, HCQA successfully completed its project to provide Referral Registry services throughout the state. Later in the year, a labor arbitrator issued an award that changed the CBA to include a wage schedule based on lifetime hours worked starting at $9.73 per hour, with top wages of $11.07 per hour by the end of the 2007–2009 biennium. And, the arbitrator increased state contributions for healthcare to $585 per month for each eligible homecare worker. The legislature approved funding for this CBA in early 2007.

In 2007, the legislature also directed HCQA to co-chair a workgroup of the Washington State Long-Term Care Task Force. This workgroup was established to evaluate training requirements for long-term-care workers with respect to the quality of care provided to vulnerable people across all home- and community-based long-term-care settings. The workgroup was to make recommendations relating to appropriate number of basic training hours, content of basic training curricula, and development of criteria to certify new long-term-care workers. The workgroup was unable to reach a consensus on what number of hours should be required for training, but was able to make progress on recommendations for training curricula. A final report was issued in December 2007.

In spring 2008, the legislature directed SEIU and the state to form a training partnership to provide training for homecare workers. By this time, the Referral Registry was operating in local offices around the state through fourteen separate contracts with organizations including area agencies on aging, homecare agencies, and a health service agency. In 2009, the governor signed a cost-saving bill closing HCQA, along with approximately twenty other small boards and commissions. The HCQA consumer board was dissolved, and the Referral Registry was transferred to the Department of Social and Health Services, where it continues to provide IP referral services for consumers. The HCQA’s nine-member board held a steadfast commitment to improving the quality of in-home care services and provided a bedrock of support for consumer rights, especially consumer choice. Its elimination resulted in the loss of an effective vehicle for consumer input and direction in long-term-care policy issues.

Because of the recent recession, the CBA has changed little since 2009. The SEIU 775 Training Partnership is up and running and provides all required training to approximately 35,000 IPs and agency providers covered by collective bargaining agreements. The SEIU 775 Multi-Employer Health Care Trust now provides health insurance for approximately 12,000 individual providers and agency homecare workers.

The Dear Cost—and Impacts—of Bargaining
Collective bargaining has had a significant impact on long-term-care costs in the state of Washington. The 2003–2005 CBA labor agreement increased state costs by $26.6 million, the 2005–2007 CBA increased costs by $41.5 million, and the 2007–2009 agreement cost the state an estimated $60.8 million. Today, the cost of health insurance alone for IPs and agency workers has
been estimated to be as high as $50 million per year in state funds. This upward trend in costs will continue as issues such as increased training hours, worker retirement benefits, and overtime become more prominent in negotiations between the state and SEIU.

**Long-term impacts**

A broad mandate of the HCQA was to encourage stability in the in-home care workforce through collective bargaining, which was borne out, according to several studies they conducted through Washington State University. In view of the current economy, it is unclear how much of an effect collective bargaining has had on stability, recruitment, and retention from 2009 up to the present. At the height of the recession, there was a significant increase in applications for worker placement on the registry and IP turnover continued on a slightly downward trend.

**The HCQA legacy**

A product of HCQA, the Referral Registry continues to enhance consumer’s ability to obtain services from qualified individual providers, and serves as an effective tool for workers seeking employment. However, eliminating the HCQA was a much larger loss for consumers, as HCQA was the only consumer-run agency in state government. Although consumers will still be able to effectively advocate for themselves through other organizations such as the Governor’s Committee on Disabilities and Employment, the Senior Citizens’ Lobby, AARP, and the Governor’s State Council on Aging, it is doubtful in the continuing recession that another consumer-controlled agency will be established with the same authority in the near future.

The in-home care program continues to be a major part of Washington State’s long-term-care system of services, and was a pioneer in consumer self-directed care for older and younger persons in need of assistance who wanted to remain in community. Only a few other states have developed such widespread statewide in-home service options for those in need of long-term-care services. The large majority of consumers receiving homecare services use the individual provider program as their service of choice because they prefer to direct their own care. Those consumers who prefer to have an in-home service agency to provide their care have that option. One of the strengths of Washington State’s long-term-care service system is that consumers have options in choosing the type of care they want and need to meet their individual long-term-care needs.

The SEIU’s organization of the homecare workers in Washington State has had a major impact on the long-term-care system. Through their union, homecare workers have been strong advocates, working with the governor, the legislature, and other decision makers to improve the long-term-care service system. They have become the most influential lobbying group in the long-term-care arena in Washington—even more powerful than the two state nursing home associations.

There is little doubt that homecare workers have seen significant improvements in their wages, fringe benefits, and working conditions. A case can also be made that the quality of care provided to consumers has benefited from the union organization of the homecare workers.

Kathy Leitch worked for the Washington State Department of Social and Health Services for over thirty years, helping to increase the home- and community-based options available to consumers, and significantly reducing the Medicaid nursing home census. Rick Hall is the former executive director of the Washington State Home Care Quality Authority and served as the state’s chief negotiator in collective bargaining with the Service Employees International Union. Charley Reed is on the AARP Board of Directors and is a long-term-care consultant for his firm, C.E. Reed and Associates, in Olympia, Washington.
On February 9, 2006, *The New York Times* published an article by journalist Jane Gross (Gross, 2006) that described Beacon Hill Village in Boston. This unique nonprofit organization was founded in 2002 by a group of older people in the downtown and Beacon Hill areas of Boston who were determined to “age in community”—in their homes, but with the services and supports they needed to stay connected to community, family, and friends. The founders’ goal was to stay in control of their lives rather than rely on private social services or government agencies for solutions. They wanted to design their own lifestyles and create their own futures. Not finding a model that matched their vision, they created their own. Today, as Beacon Hill Village celebrates its tenth anniversary, sixty-six Villages are open across the country, with approximately 13,000 members. At least 110 more Villages are in development.

Gross’s article prompted more than 3,000 requests for information and assistance. Beacon Hill Village responded individually to many requests, created a two-part Founder’s Manual, and held the first national Village conference in 2007 that attracted more than 200 people. In response to growing national interest in the Village model, Beacon Hill Village and NCB Capital Impact (a nonprofit Community Development Institution), joined forces in 2010 to launch the national Village to Village Network (VtV Network).

The Village Model
Villages empower older adults to remain in their own homes and communities as they age. Villages are designed, built, and governed by those who are going to use them; they focus on community-building and the “non-medical side of healthcare”—the social and practical supports that, when absent, may limit peoples’ ability to live independently or comply with a medical plan of care, which can lead to poorer health.

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The founders of the Village Movement had a visionary goal: to stay in control of their lives—and create their own future.

The Village Movement Empowers Older Adults to Stay Connected to Home and Community

Aging in place is not only elders’ preferred choice, but it may be the only affordable and available option for many older Americans.
Villages share the following “hallmark” characteristics:

- they are self-governing, self-supporting, grassroots membership-based organizations;
- their organizational structures, programs, and services vary in response to the needs of their members and resource gaps in their communities;
- they consolidate and coordinate member services, which are provided through screened volunteers and providers;
- they are holistic, person-centered, and consumer-driven;
- they create innovative strategic partnerships that leverage existing community resources without duplicating existing services, thereby creating “win–win” scenarios that bring additional business to their partners and provide additional services for members; and
- they promote volunteerism, civic engagement, and intergenerational connections.

Why Villages?
The American population is aging and living longer. Baby boomers—the oldest of whom began turning age 65 last year—can expect to live into their eighties and nineties, giving them a twenty-to thirty-year period of phased retirement, encore careers, volunteer activity, possible roles in raising grandchildren, supporting their children, or being caregivers to other family members. As they age, nearly all will have at least one chronic condition and many will have several. Their health and mobility status will likely decline gradually over time, with intermittent periods of in-patient care and more intense medical needs. Some will live with other people; some will live alone or become widowed or divorced during these years. About 80 percent of them will own their own homes.

Yet many people may find that their homes will have lost value and their retirement savings will be diminished due to the 2009 real estate and economic crisis. And many will be shocked to learn that Medicare does not cover long-term services and supports (LTSS), and that they will need, on average, three years of assistance, including one year in a nursing home (about $80,000) and two years of paid care at home (about $36,000).

These tough circumstances point to a hard reality: aging in place, in the community, is not only the preferred choice of older adults, but it may be the only affordable and available option for many older Americans. While publicly funded systems and services exist for those with low incomes, the same supports do not exist for the middle class. On the bright side, however, the Village movement has emerged to fill this gap.

What Villages offer
Villages are “focal points” for their members—with one phone call, members obtain information and guidance, access to services and programs, and assistance in navigating the confusing maze of LTSS that exists in most communities. Services are provided by a mix of volunteers, members, staff, other community organizations, and contracted providers. Some are free with membership, and others may require a fee.
While there is no standard member benefit package among Villages, Villages generally offer services in the following categories:
- one number to call for any information or assistance members need;
- member-to-member volunteer support;
- assistance with daily living needs, such as transportation, grocery shopping, light home maintenance, check-in calls, and medication reminders;
- health-related supports, such as Village-run “MedPal” programs in which trained volunteers help members navigate the medical system and provide assistance with hospital-to-home transitions;
- social, cultural, educational, and wellness programs that create a strong community and help members remain active and engaged;
- assistance with arranging homecare and other services performed by screened providers; and
- “early care management” that identifies and brokers services for members, providing guidance and support that can prevent crises.

How Villages are structured and run
About 75 percent of Villages are freestanding nonprofit organizations; others are consumer-directed programs of larger multiservice organizations serving elders. Village revenue comes from membership fees, grants, in-kind donations, individual donations, and sponsorships. While nearly all Villages start with an all-volunteer planning committee, most raise money over time to hire a small staff, usually an executive director, volunteer and member services manager, and office support. Social-work skills are an asset to Villages; some executive directors are social workers and many Villages have retired social workers among their members. Village boards of directors consist primarily of Village members.

Early demographic research on Villages found that membership numbers range from 100 to 800 people, with an average membership of 200. Average annual membership fees are $430 for an individual and $600 for a household. Many Villages also have reduced-fee memberships for people who might find the standard fee a barrier to membership. (Scharlach, Lehning, and Graham, 2010).

Sixty-six Villages are now open across the country, and more than 100 are in development.

Villages Connect with Public Funding
While Villages have developed without federal or state funding—and to a large degree outside the traditional aging services network—state and local interest in Villages and other member-driven models is growing. Many counties and cities are involved in aging-friendly initiatives focusing on both the built environment as well as LTSS. States are interested in choice, prevention, and healthy living for all residents, motivated in part by keeping residents from spending down to Medicaid eligibility, which

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**Judy and Capitol Hill Village**

While working in her garden on Capitol Hill, Judy, a 59-year-old federal employee, fell, breaking her left arm and right leg in multiple places. After her hospital stay and rehabilitation therapy, she decided not to move into assisted living, instead returning home with the support of staff and volunteers of Capitol Hill Village. Village volunteers outfitted her home and assisted with meals, transportation, homecare, shopping, companionship, and other supports that ensured a safe recovery in her own house. Judy is now nearly independent. She recently told her story to her co-workers during United Way’s Combined Federal Campaign, building awareness of Capitol Hill Village and raising critical funds to support Village operations.
then increases the financial demand on states’ already strained safety nets.

For example, the state offices on aging in Michigan, Ohio, and Pennsylvania are looking at ways to serve as catalysts for member-driven models like Villages and co-housing to meet the LTSS needs of older adults in neighborhoods and communities. Georgia was awarded a 2011 System Integration grant from the Administration on Aging; this will be used in part to contract with local area agencies on aging statewide to develop Villages in their communities.

In the District of Columbia, Mayor Vincent Gray has directed the Office on Aging to help bring the Village model to every neighborhood in the city, particularly lower income wards. The Office on Aging has also helped subsidize reduced fee memberships at Capitol Hill Village. In the broader D.C. Metropolitan Area, where twenty-eight Villages are operating or in development, Fairfax County is providing in-kind support to help with Village planning efforts and Montgomery County has funded a Village to Village Network membership for local Village founders. And in Santa Monica, California, the county is helping fund reduced fee memberships for WISE & Healthy Aging’s Village, WISE Connections.

Additionally, in several states, Villages are collaborating with senior centers through joint programming, member and volunteer recruitment presentations, and reciprocal board roles. Discussions are also underway in some areas between Villages and affordable housing sites.

The Village to Village Network

Through the investment of start-up funds from the MetLife Foundation, Hearst Foundation, and Milbank Foundation for Rehabilitation, NCB Capital Impact, with its partner Beacon Hill Village, launched the Village to Village (VtV) Network (www.vtvnetwork.org) in January 2010. The VtV Network is a national, membership-based, peer-to-peer network of Villages that draws on the expertise of member Villages and VtV staff to support the continued growth of open Villages and to connect developing Villages with the expertise and resources they need to become operational. This initial funding has allowed the VtV Network to promote the Village model as a replicable community approach to aging; help identify sustainability strategies for Villages; conduct research on Village development; and create a Web-based learning exchange among Villages nationally. The VtV Network currently has 185 organization members in thirty-six states.

The VtV Network’s members include 90 percent of open Villages as well as other community-based organizations, area agencies on aging, and local businesses. Members are able to access information, technical expertise, tools, and research that will support their work at the local level. Services offered by the VtV Network include an information phone line; a searchable U.S. Village directory; three to four webinars a month on all aspects of starting and operating a Village; member-initiated discussion forums; a shared-document library; a media archive; and a discounted, customized website platform for members to use to manage membership records and service requests. The VtV Network also hosts an annual national Village conference and regional conferences (as funding permits).
A top priority for the VtV Network is driving research to evaluate Village organizational structures, membership characteristics and services, sustainability, and impact on members’ well-being. Village research has been led by Dr. Andrew Scharlach, director of the Center for the Advanced Study of Aging Services (CASAS) at the University of California, Berkeley. Past CASAS research included three national demographic and organizational studies of Villages. Current research includes a nine-site Village Expansion initiative funded by the Archstone Foundation in California and an evaluation of ElderHelp of San Diego’s Concierge Club, which serves frail and isolated elders in San Diego. Additional research is underway to compare characteristics of Villages and Naturally Occurring Retirement Communities Supportive Services Programs.

Current findings from individual Villages indicate positive results from Village services and programs. Members of the One Call Club in Knoxville, Tennessee, have shown improvement or stabilization of health, social functioning, and activities of daily living, delayed need to move to assisted living or a nursing home, and decreased hospitalization rates (McCutcheon, Hadjiharamou, and Homer, 2011). ElderHelp of San Diego members report greater awareness of community services, an increase in going outside the home for day-to-day activities, and a greater likelihood of staying in their own homes as they age (ElderHelp of San Diego, 2011).

What the Future Holds
While the Village movement is young, the model continues to resonate with people throughout the country and internationally. It has been described as a “true innovation” at a time when the safety net is being dismantled and baby boomers are beginning to experience the gap between what they (and often their parents) will need over the next twenty to thirty years and what they can afford.

The movement is strong and growing, but challenges exist. Village leaders are active in balancing the model’s flexibility with the need for strong business models. Financial sustainability
depends on drawing in members from ages 50 through 90-plus, for both revenue- and volunteer-building purposes. Other challenges include preparing for the health needs of members, supporting family caregivers, taking an active role in integrating and leveraging local resources, and developing diverse revenue streams.

As the Village model evolves, Villages and the Village to Village Network will seek to impact positive change in a variety of ways. These include adapting the model to lower-income communities; developing strategic national partnerships; supporting state and regional Village networks; continuing to build the evidence base for sustainability, improved health outcomes, and cost savings; being “at the table” with federal, state, and local governments to pursue innovative aging-in-community options; and exploring connections with Medicare and Medicaid, healthcare and long-term-care insurers, and Affordable Care Act provisions.

There is a saying in the Village world: “If you have seen one Village, you’ve seen one Village.” By definition, Villages are unique, representing the needs and desires of their individual members and communities. What is universally true in the Village movement, however, is a commitment to finding new ways to help people age in community. With little hope of government financing for direct LTSS for the middle class, it is incumbent upon communities to make consumer-led-and-driven entrepreneurial models like Villages the norm in every town and city. States, cities, and counties can be part of this effort by being catalysts for innovative planning that addresses the needs of older adults across income levels.

While the challenge is clear, the good news is that growing recognition of the link between non-medical supports and improved health outcomes for elders contributes to acceptance of aging-in-community models that create greater choice and security for our nation’s older adults.

References


Disparities in Assisted Living: Does It Meet the HCBS Test?

As assisted living evolves, there are many challenges—from equitable access to remaining true to original design principles.

Since the late 1980s, states have considered assisted living (AL) a key home- and community-based service (HCBS) option for rebalancing their systems of long-term services and supports (LTSS). Assisted living has also been a solution for millions of older adults and their family members when increased frailty makes remaining at home unmanageable.

Early AL proponents viewed it as a supportive housing model preferred by consumers, and one that should be available to all those who need LTSS. In reality, the AL concept has evolved into highly differentiated organizational models with often contradictory structures, practices, and values orientations. These contradictions lend support to critics who say the AL industry has fallen short of its early promises, first because some AL residences resemble institutions, and second because access to AL is often limited by income, race and ethnicity, and geographic area.

Characteristics of Assisted Living

Using a broad definition of AL for elderly people, there are about 31,100 licensed AL providers in the United States with a capacity to serve almost one million residents (Park-Lee et al., 2011). Generally, AL communities are defined as non-nursing home residential settings providing room, board, assistance with activities of daily living, and twenty-four-hour staff. The physical features of AL communities differ between and within states. About half are small homes serving four to ten residents in private or shared bedrooms, which are either licensed under distinct adult foster home rules or all-inclusive AL rules. In terms of resident capacity, larger communities serve a majority of AL residents (See Figure 1, page 119). These include newer residential care homes built as assisted living and older board-and-care homes with a mix of private and semi-private rooms. The most recently developed AL type comprises studios and one-bedroom apartments that can be shared or not, depending upon the resident, and have full private bathrooms and kitchenettes.

Assisted living organizations offer a varying scope of services. Core services tend to include some level of assistance with personal care, medication supervision, social and recre-
ational activities, meals, and housekeeping. The greatest variation is in the intensity and frequency of personal care assistance provided by the organization, and the availability of specialized health and behavioral services. Recent industry figures show that 24 percent of providers do not provide therapeutic diets, 12 percent do not provide nursing services, and 48 percent lack wandering or behavior management (American Association of Homes and Services for the Aging, 2009). Without these and similar services, some AL settings may only partially substitute for nursing homes.

Can Assisted Living Be Part of HCBS?

Pioneers in AL imagined their communities as blending selected elements of traditional elder housing and long-term care. Settings would be residential and apartment-like, and staff would be able to directly provide or arrange for the maximum range of services one could receive at home. To distinguish themselves from nursing homes, some AL leaders used terms like “tenant” rather than “resident” and “move out” rather than “discharge.” A few states and many affordable housing projects have adopted “housing with services” AL models in which services are coordinated with outside providers rather than using in-house staff.

In affordable AL settings, “base” or “room and board” charges may be calculated separately from other personal and healthcare services provided or arranged by the AL community; this is in order to accommodate public-lending requirements and Medicaid waiver restrictions. Specifically, Medicaid waiver dollars can only be used to pay for services in non-institutional settings. This unbundling of housing and service costs is considered one of the features distinguishing AL from nursing homes.

The notion that AL is housing is at the heart of its acceptance as an HCBS service under Medicaid waivers. When AL is covered under HCBS waivers, states establish the conditions for provider participation. Eligible residents must meet the state’s nursing home–level of need criteria. In turn, AL providers decide whether they will accept Medicaid residents. Most states allow (but do not require) AL providers to maintain the service capacity needed to serve very frail residents. To the contrary, many states specify that AL cannot retain consumers once they incur certain types or levels of disability. As noted further on in this article, when AL settings adopt practices restricting freedom of movement and lifestyle choice, they become more institutional.

When Does Assisted Living Deserve HCBS Designation?

In 2011, the Centers for Medicare & Medicaid Services (CMS) proposed redefining AL residences that could qualify as HCBS under Medicaid waiver rules. Such rules could potentially disqualify many elders living in AL from receiving Medicaid-funded services, and they met with strong opposition from provider groups, consumer advocates, and state policy makers. Specifically, proposed rules would exclude non-apartment–style AL, which have historically served low-income residents under state Medicaid waiver programs. Other disqualifying criteria included being designed for specific disabilities or being located in a “custodial

Figure 1. Assisted Living Supply Distribution by Size

<table>
<thead>
<tr>
<th>% of Residences (n=31,100)</th>
<th>50%</th>
<th>16%</th>
<th>28%</th>
<th>7%</th>
</tr>
</thead>
<tbody>
<tr>
<td>% Resident Capacity (n=971,900)</td>
<td>10%</td>
<td>9%</td>
<td>52%</td>
<td>29%</td>
</tr>
</tbody>
</table>

Source: Park-Lee et al., 2011.
care” facility, which is what most AL settings essentially provide. Less controversial conditions included having individual leases, lockable units, freedom to receive visitors and leave the residence, ability to age in place, and person-centered service planning. These draft rules represented the CMS’ attempt to address reported inconsistencies found in AL, particularly in more institutional settings.

Variability in the Assisted Living Environment

In their ideal form, AL settings provide a normalized environment with residential features and more services, designed to support privacy, autonomy, dignity, and individuality. However, many AL communities diverge from this ideal, partly because industry associations and most states have grandfathered in older board-and-care homes that cannot be easily adapted. And, newer communities may adopt institutional structures and practices, often to address safety and health concerns, or limited resources.

The residential versus institutional nature of an AL community is clear from the physical environment. Numerous publications have provided guidelines for making AL more homelike, accessible, and integrated with the surrounding community. They emphasize minimizing the scale of buildings and common areas; using residential furnishings, materials, and treatments; providing personal living spaces that maximize privacy and control (e.g., lockable, unshared living space and bathroom); and providing outdoor spaces that can be easily accessed by residents. Yet adopting these basic design practices remains uneven, as one finds AL common areas with large institutional lobbies, clinical reception desks, long corridors, blinking call lights, nursing stations, and so-called companion suites furnished with hospital beds.

Certain internal practices and policies also render AL environments more institutional, like using large medication carts, justifying the practice as being more safe and efficient. To save time, staff may begin using public address systems to make community announcements, and letting themselves into residents’ rooms after only a perfunctory knock on the door. Convenience and family pressure also encourage institutional practices such as closing the dining room between meal times, or checking in on residents at night.

Maximizing resident autonomy, choice, and control are the foundations of non-institutional AL practice (Kane and Cutler, 2009). This includes enabling residents to direct how services are provided according to their preferences and needs. It also involves residents having control over their personal space, as well as how and with whom they spend their time, within and outside the residence. Lack of control over remaining in AL settings has also been proposed as a feature that makes them less community-based. As noted below, state regulations and policies shape AL service capacity and residency criteria. State-to-state variability has continuously raised questions about how effectively AL settings can accommodate consumer preferences to age in place and minimize nursing home moves.

Disparities in Access to Assisted Living

There is growing concern that the same segments of the population facing barriers to quality housing and healthcare also lack equitable access to AL—particularly to the newer, less institutional apartment-style settings.

Rural access lower to nil

Although most older adults in the United States live in metropolitan areas, older people represent a larger proportion of non-metropolitan and rural populations who are more likely than their urban counterparts to be poor (Colello, 2007). National studies have reported that rural counties have a lower per capita AL supply than do urban counties. Rural areas are also more likely to have no AL settings at all (Stevenson and Grabowski, 2010). One likely explanation is the perceived lack of demand, both in terms
of population size and financial resources, for larger apartment-style residences. Limited and complex financing options for new projects may also disproportionately hinder rural supply growth.

Fewer older minorities use assisted living
Older people of color are less likely to use AL, both in comparison to their proportion in the national population, as well as to their use of other LTSS options. During the late 1990s, there was a relatively small and possibly declining proportion of racial and ethnic minorities in AL (Spillman, Liu, and McGilliard, 2002). Howard and colleagues (2002) found that racial separation was occurring across and between facility types. Specifically, African American residents were more likely to be found in nursing homes (24 percent) than in all three types of AL, whether smaller (13 percent), traditional board-and-care (5 percent), or newer apartment-style models (4 percent). Price may explain some of these differences, given lower income levels and higher poverty rates among older people of color. Plus, AL residences are less likely to be found in counties with a higher proportion of minorities (Stevenson and Grabowski, 2010).

Assisted living residences with a higher proportion of minority residents have different characteristics (Howard et al., 2002; Salmon et al., 2004). Such buildings tend to be smaller, older, have lower monthly charges, and employ minority administrators. Living units are more likely to be bedrooms with shared bathrooms rather than private apartments. Residents are more likely to be younger, Medicaid-eligible, and have developmental disabilities or chronic mental health issues. Possibly, too, these smaller AL homes serving minority residents face greater hardships related to the growing burden of regulatory requirements (Carder, Morgan, and Eckert, 2006).

Cultural barriers
Addressing racial and ethnic disparities in AL use will require addressing largely unexamined cultural barriers. Lower use of AL by older people of color may be partly explained by a greater preference for family caregiving and a stronger sense of family responsibility among some groups. However, stereotypical views about group preferences may hinder developing effective cross-cultural outreach efforts.

Another likely explanation is that typical AL settings lack features that would be considered culturally meaningful or compatible with the values, beliefs, and behaviors shared by some groups. In the healthcare and aging services fields, fostering cultural competency and cultural humility are considered both organizational- and individual-level interventions for ensuring more equitable access to appropriate and high-quality services. Such approaches have received much less attention within the AL industry. As with other HCBS, engaging members of underserved communities and developing constructive working relationships could help build cross-cultural understanding. Collaborative efforts would inevitably help identify opportunities for adapting practices, respecting traditions, and adopting approaches that would be considered more culturally appropriate and acceptable.

Lower income residents barred by cost
Compared to the population of older adults in the United States and to nursing home residents, lower income residents are less likely to be served in AL. Although the AL industry grew rapidly in the late 1990s, the proportion of lower income AL residents shrank (Spillman, Liu, and McGilliard, 2002). High monthly costs and limited financial assistance continue to be the main access barriers. Most older adults have in-
comes well below what a typical AL community charges. In 2008, the average base annual cost of AL was about $36,000 per year (MetLife, 2008) yet at least 77 percent of adults ages 80 or older have incomes below this amount.

Opportunities to better serve LGBT elders

Few studies have examined AL use by lesbian, gay, bisexual, or transgender (LGBT) older adults, largely because survey instruments rarely ask about sexual orientation or gender identity. Nevertheless, there is some indication that LGBT elders face negative experiences with and attitudes toward moving into assisted living. Faced with homophobic attitudes and discriminatory behavior from managers, staff, and fellow residents, LGBT elders may either avoid moving into AL or hide their sexual orientation and gender identity once they do move. Efforts to develop LGBT-targeted senior housing and AL settings have had mixed to very limited success due to financing, development, and marketing challenges. Policy- and organizational-level interventions for making typical AL settings more welcoming to LGBT elders include amending housing laws to include LGBT non-discrimination policies and providing cultural competence training (Grant, et al., 2010). In 2010, the National Center for Assisted Living developed a training program for aging services providers.

Paying for Assisted Living

According to industry reports, most residents primarily rely on their personal resources to pay for AL (See Table 1, page 123). “Private-pay” options include personal income and assets, family assistance, and long-term-care insurance. It is believed, though not well documented, that low- to moderate-income residents use home sale proceeds to finance AL, along with other savings and investments. Families are the primary or secondary source of payment for a third of residents. Recent economic conditions have made family help more difficult, perhaps partly explaining a reported 23 percent decline in the proportion of residents relying primarily on family financial support between 2006 and 2009, according to the 2009 Overview of Assisted Living, produced by American Association of Homes and Services for the Aging (now LeadingAge) and four other partner organizations (AAHSA, 2009). Long-term-care insurance benefits are the least common private payment source, likely because of limited coverage among the oldest old.

Medicaid benefits and Veterans (VA) programs are the most common public payment sources for AL. Monthly SSI payments amount to about a third of what the average AL charges, but are the most common source of public payment because other sources may be layered on. Medicaid programs in all but ten states will reimburse some form of AL, although the financing strategy will have different implications for resident eligibility, provider participation, and program size. Although VA benefit supports are even less common, a small and growing number of older AL residents are covering their monthly costs through the Aid and Attendance and House-bound programs, which provide a cash benefit for eligible veterans, their spouses, or dependent parents.

Policy and Organizational Access Barriers

State and, to a lesser extent, federal regulations and finance policies have responded to AL market developments, while generally providing favorable conditions for the industry to grow and diversify. Assisted living residences must adhere to state licensing regulations specifying physical and operational blueprints. State and federal agencies have also provided financing to build new projects and revenues with direct subsidies to eligible residents and service payments to providers. Each
state’s AL policies are unique, and have evolved with the shifting political and economic landscape. Licensing regulations specify design requirements that may be more or less residential, and minimum services that may be more or less expansive. Most states specify that ALs should support values, such as privacy, individuality, and a home-like environment, but only eleven of these also require private apartments (Mollica, Sims-Kastelein, and O’Keefe, 2007). More common and less objective residency criteria allow providers to move residents when resident needs exceed the facility’s service capacity. Over time, state regulations have become more permissive in allowing providers to serve residents with higher care needs, sometimes by asking for individual waivers and rules. However, providers can and do adopt residency policies that may be more restrictive than required by state policies.

### An aversion to Medicaid

A key barrier for lower income residents to move into and remain in AL is the provider’s unwillingness to become a contracted Medicaid provider. Inadequate payment is the biggest disincentive. The wider the gap between a provider’s private monthly rates and the state’s reimbursement, the less likely a provider will serve any Medicaid residents. As payment gaps widen over time, particularly due to recent state budget crises and eroding payment rates, contracted providers may limit the number of new Medicaid residents they will accept. Some providers may also choose to terminate their Medicaid contracts. Besides low payment levels, AL providers also report an aversion to Medicaid programs, which they associate with higher operating costs. Despite the rapid overall growth in Medicaid AL during the last decade, program penetration remains modest. In 2010, about four in ten AL residences in the nation served at least one Medicaid AL beneficiary (Park-Lee et al., 2011). However, Medicaid AL beneficiaries likely represent a much smaller proportion of the total AL supply.

Access to apartment-style AL among lower income residents varies by state because Medicaid AL policies vary by program size, reimbursement adequacy, and eligibility criteria for providers and residents. Unless the state provides a higher reimbursement rate for apartment-style AL (as Oregon does), lower income residents will have less access to the more recently developed AL apartments that have targeted a middle- and upper-income resident population. In Florida, older AL residences may have units shared by up to four unrelated

### Table 1. Assisted Living Resident Payment Sources

<table>
<thead>
<tr>
<th></th>
<th>Primary</th>
<th>Secondary</th>
</tr>
</thead>
<tbody>
<tr>
<td>Private</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Self</td>
<td>66%</td>
<td>30%</td>
</tr>
<tr>
<td>Family</td>
<td>11%</td>
<td>24%</td>
</tr>
<tr>
<td>Long-term-care insurance</td>
<td>6%</td>
<td>9%</td>
</tr>
<tr>
<td>Public</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medicaid</td>
<td>13%</td>
<td>4%</td>
</tr>
<tr>
<td>SSI/State Supplement</td>
<td>3%</td>
<td>17%</td>
</tr>
<tr>
<td>VA</td>
<td>0%</td>
<td>7%</td>
</tr>
<tr>
<td>Not reported</td>
<td>2%</td>
<td>8%</td>
</tr>
</tbody>
</table>

Source: 2009 Overview of Assisted Living, AAHSA.
persons, while newer ones are limited to two.

The Evolution of Assisted Living
Assisted living represents a growing and evolving form of LTSS that has historically been considered a key HCBS option. The prevalence of more institutional features in some AL has led various stakeholders to begin proposing more person-centered approaches and policies. Their widespread adoption will likely be gradual, given the decentralized policy environment and the structure of the AL industry. More challenging will be addressing the root causes of limited access for segments of the older population. The current period of fiscal austerity provides little hope that most states will adopt policies designed to expand the supply of and access to affordable AL in the near future. Yet restrictive residency policies and uneven service capacity can further undermine efforts to expand Medicaid AL funding, particularly when increased frailty among residents results in avoidable nursing home placement. Assisted living will likely continue evolving in multiple directions over time. Both government and organizational policies will determine to what extent segments of the industry remain HCBS settings that become more accessible for all elders, or whether they become more restrictive, both in terms of how they operate and who they serve.

Mauro Hernandez is the chief executive officer of Concepts in Community Living in Clackamas, Oregon.

References
When faced with the prospect of needing a nursing home–level of care, three-quarters of people over age 45 say they want to stay in their home as long as possible. Nearly two-thirds say they would like to remain in their local community because it offers proximity to friends, family, and places they want to go (Keenan, 2010). These preferences, and associated governmental cost-savings (Kaye, LaPlante, and Harrington, 2009), have driven the rapid expansion of the Home and Community-Based Services (HCBS) program over the last thirty years.

This article proposes that Green House homes, homes of six to twelve people licensed as nursing facilities that deliver person-directed care through radically redesigned environments and organizational structures, can be part of the home- and community-based spectrum when integrated into residential communities using a scattered-site approach (single or paired homes embedded into residential neighborhoods). In this configuration, Green House homes can provide a community-based option for people with high service and clinical needs who, due to individual circumstances or finances, lack other non-institutional options. The community-integrated Green House concept is illustrated by two Green House homes operating in a neighborhood in upstate New York.

**Nursing Homes Meet The Green House Project**

Unfortunately, not everyone can remain in their own home or a family member’s home. Despite a clear preference for home- and community-based care, approximately 1.2 million Americans currently live in institutional settings removed or segregated from their communities. This is especially true for low-income elders and people with complex needs who lack access to sufficient and affordable services at home (Feng et al., 2011). Unfortunately, the number of people using nursing home services is expected to grow as America’s population ages (Lakdawalla et al., 2003).

With many people continuing to rely on nursing home services for the foreseeable future, The Green House Project focuses on two goals.
The first goal is to create a different kind of home for people who will continue to need a full range of care and clinical services—homes that assure quality of life and quality of care, meet state and federal nursing home standards, and operate at the same or lower costs than traditional nursing homes. Today, 126 Green House homes operate across thirty programs and sixteen states; each home is a thoroughly residential environment for six to twelve people, with radically transformed operations. Operating Green House programs range from one to sixteen homes. The largest project in development will have twenty-four homes, in a high-rise configuration, in a residential neighborhood of a major U.S. city.

The second goal is to disseminate a community-based model of Green House homes, each licensed and certified as a nursing home, while meeting the community integration goals of HCBS and the Independent Living Movement. This means creating and integrating Green House homes, house by house, into the communities where older people live and where many want to remain. Creating this option is a critical next step to meet the community-dwelling preference for those who will need nursing home care, and will allow them to benefit from the lessons learned and achievements wrought by the HCBS revolution over the last thirty years.

Can a Medicaid-Certified Nursing Home Achieve HCBS Goals?

Some define dependence as the need to rely on others for the most basic necessities of life. However, human life depends upon an ongoing reliance on others: we are all dependent. It is the form this reliance takes that can help shape well-being. Building successfully integrated homes and communities that meet HCBS goals means that we strive to provide a sanctuary where elderhood can flourish as a developmental stage. The Green House Project’s design supports this distinctive form of community integration by generating human warmth through a de-emphasized hierarchy and being committed to small-size, strong relationships and openness to the surrounding community.

Baby boomers are the ideal generation to propel this integration movement. With a higher level of education than any previous generation and the well-established habit of reinventing social norms, baby boomers are poised to embrace the concepts of intentional communities and approach old age as a time of growth rather than decline.

However, despite growing demand, many believe that anything licensed as a nursing home must, by definition, be an institution. The Green House model challenges this notion—separating the licensure category for nursing homes from institutional practices. This allows us to preserve nursing home clinical service and reimbursement levels within a de-institutionalized model.

We do this by creating clusters of small homes, each serving six to twelve people. The homes deliver person-directed care through a radically transformed operating model that allows each house to operate independently in the areas of direct care and homemaker responsibilities (e.g., cooking, laundry, and housekeeping). This redesign provides much greater flexibility in schedules and approaches to meet individual needs, while allowing CNAs to spend significantly more time developing relationships with the people living in the home (Sharkey et al., 2010). Economies may come through more efficient workforce design, combined with shared clinical, administrative, and purchasing functions.
The redesign provides a reliable and strong person-directed, relationship-based setting where people can age in place successfully and have complex medical, physical, and cognitive needs met. The Green House model prefers to operate under a nursing home license whenever possible to assure that people requiring intensive long-term-care services have access to a consumer-directed model without the regulatory and financial limitations encountered in other long-term-care settings (e.g., assisted living, board-and-care).

Operating as a nursing home allows Green House homes to deliver services within the person-directed philosophy of HCBS. This means that these homes are not limited by service caps and discharge requirements imposed on less clinical models of care (such as assisted living or family care homes), HCBS waiver program enrollment limits, and lower Medicaid waiver service and reimbursement levels. Moving these homes into residential neighborhoods will allow Green House homes to achieve the same (or perhaps better) community integration than many HCBS residential models, whose larger scale often separates them from residential communities due to land use restrictions and community opposition.

Given these advantages, community-integrated Green House homes, licensed and certified as nursing homes, could become an important part of state and federal efforts to meet the Olmstead mandate, which requires states to serve individuals in the most integrated setting appropriate to their needs (Olmsted v. L. C., 1999). These same Green House nursing homes could also meet the spirit of the Centers for Medicare & Medicaid’s (CMS) recently proposed definition for HCBS service settings: “HCBS settings are integrated in the community and may not include: facilities located in a building...that provides inpatient institutional treatment or custodial care; or in a building on the grounds of, or immediately adjacent to, a public or private institution; or a disability specific housing complex designed expressly around an individual’s diagnosis, that is segregated from the larger community.” (Federal Register, 2011).

Unfortunately, today’s predominant nursing home model is the product of a narrow view of economies of scale and control. This institutional approach collects expertise, labor, equipment, management, and elders in one location using the same scale and assembly-line logic that led Andrew Carnegie to build mammoth steel mills. Efforts to create economies of scale through concentration and specialization have encouraged nursing homes to develop as large and task-segregated institutions. Sadly, people do not respond well to this approach (Harvard School of Public Health, 2011).

In fact, being “cared for” along with 100 to 300 other similarly situated people in an institution carries significant unexpected financial and personal costs (Goffman, 1961; Jenkens et al., 2011). The Green House model has proven that nursing homes can be built on a human scale—one that creates community within and outside of the house at the same or lower cost than the institutional industrial approach (Jenkens et al., 2011). A major theory of the Green House concept—a theory that may seem counterintuitive to some—is now demonstrated in the open Green House homes; it shows that economies may be achieved in disaggregated operations through more efficient workforce design (i.e., the versatile CNA position), combined with shared clinical, administrative, and purchasing functions.

Community-Integrated Green House Nursing Home: Concept Test

St. John’s Home in Rochester, New York, which is a multilevel retirement community with a 475-bed nursing home committed to person-centered care, despite the limits of a large campus, opened the first two community-integrated Green House homes in February 2011. Similar to many Green House providers, St. John’s initially planned to build fourteen
Green House homes on a congregate campus. In 2007, their administrative team met with New York state officials to discuss the project. Tom Jung, then director of Health Facility Planning, challenged the group to consider building the ideal community-integrated Green House homes described in the book, *What Are Old People For?* (Thomas, 2004).

St. John's responded without hesitation, beginning a four-year partnership with The Green House Project to design and implement the first truly home- and community-based nursing home. This effort included designing a physical environment that blends style, scale, and appearance with the independent homes surrounding the two Green House homes, while meeting all skilled nursing home construction standards.

It also involved translating standard Green House operating practices (see www.thegreenhouseproject.org) to support a freestanding site receiving administrative, departmental, and non-nursing services from a distance. The practices were each designed to meet or exceed state and federal nursing home requirements and to work within a financially viable program.

The physical and operational organization that emerged is a new nursing home serving twenty elders in two ten-bedroom homes. The houses sit side by side and are embedded in Arbor Ridge, a new residential subdivision in Penfield, New York (see Figure 1). The homes are indistinguishable architecturally from the other homes in the development (see Figure 2 on page 129). They have the same scale and flow of a regular home and bedroom windows looking out over the central pond. There are walking paths to the backyards and decks of the neighboring families. The first residents to move into the Green House homes came from St. John’s large nursing home as the “beds” were transferred to Penfield. Over time, residents are expected to come from the immediate community.

Per New York State nursing home requirements, the paired Green House homes’ operations (licensed and certified as one provider) include a designated part-time administrator and director of nursing, eight hours of care per day by registered nurses, round-the-clock coverage by licensed practical nurses and CNAs, and a clinical and departmental support team that makes regularly scheduled and as-needed visits.

Per The Green House Project standards (which

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**Figure 1. Arbor Ridge Site Plan**

Green House homes are in lower right corner.
Figure 2. Exterior, The Arbor Ridge Development

The Arbor Ridge website (www.pmhomes.com/ArborRidge.html) describes the new Arbor Ridge residential development as “a neighborhood of luxury town homes nestled in a private wooded community with ponds, walking trails, sidewalks, and streetlights.” The Green House homes allow residents to live as a family within the larger Arbor Ridge community.

exceed New York State’s), homes provide four hours of direct-care staffing; one hour of direct nursing care per elder, per day; meals prepared in the homes; person-directed care, and substantial individualized engagement between elders and staff. The heightened nursing staff hours are balanced through self-managed teams and versatile work roles. These organizational redesigns result in an overall labor savings in The Green House model of 0.3 hours per resident, per day, compared to traditional nursing homes (Sharkey et al., 2010).

Expected Outcomes
People, both with and without cognitive impairments, who live in the community-integrated Green House homes are expected to remain more integrated into the broader community because of closer physical proximity, more individualized assistance to support participation in external activities, and having a “normalized” home that community members feel comfortable visiting. We expect that this community integration will improve clinical and satisfaction outcomes, and drive demand and revenue growth.

We do not expect that the community-integrated approach will increase development or operating costs due to the already disaggregated operating model used with campus-based Green House homes. The one cost increase that may result from community-integrated Green House homes is additional administrative burden if each location (single or paired homes) is required to have a separate state license and federal certification due to their non-contiguous locations. The single-provider approach for community-integrated Green House homes is currently under discussion with CMS. Any additional administrative costs will limit the
number of Medicaid-eligible residents that a project can afford to serve. Evaluation planned for Green House homes over the next three years will determine the measure of these expected outcomes.


Acknowledgment
The Green House is a registered service mark of The Center for Growing and Becoming, Inc., in New York State.

References


Looking back on the accomplishments and changes in home- and community-based services (HCBS) for older adults over the last thirty years, we are struck by a dramatic shift in locale and, even more impressive, a change in the perception of what older people want in long-term services and supports (LTSS). Older people's preference to stay at home rather than enter nursing homes is stable across the period. What has changed is the way policy makers, government officials, and providers think about care. As those who advise and serve older persons gradually shift their thinking, institutional care will seem less inevitable.

A Moving Paradigm

Whereas HCBS was previously viewed as an alternative to nursing homes, today, professionals seem to believe that home should be the first choice and institutions a last resort (even as we try to make institutions more inviting physically, less structured in daily routine, and more individualized in each resident's care and service). We have changed our language to match: we now call older persons “consumers” or “participants,” not “clients” or “recipients,” and use the terms “care consultation” and “care navigation” as much as we use the term “case management.” State agencies responsible for long-term care have reinvented themselves with new names—two examples are Vermont’s Division of Aging and Independent Living, and Pennsylvania’s Council on Long-Term Living—to reflect their broader mission. The former Association of Homes and Services for Aging is now LeadingAge, and its state affiliates include five associations that are simply called Aging Services, and then there is the renamed Illinois Life Services Network. These names reflect that nursing homes are not their only—or even their major—business.

Ironically, although we celebrate evidence-based practice in some spheres, this shift in LTSS has occurred with little or no empirical evidence of its efficacy or comparative effectiveness. Like the civil rights and disability rights movements before it, this change was based on doing the right thing. Since the mid 1980s, after a spate of studies on alternatives to nursing homes culminating in the Channeling demonstration (see Applebaum's article, page 21), surprisingly few studies have compared the effectiveness of

**HCBS: The Next Thirty Years**

Radical changes in the way we think about LTSS are required to make them work for more older adults.

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community and institutional care for older people. This is in part because the average disability level of the clients is substantially lower in HCBS than it is in nursing homes. Some older people with severe physical or cognitive disability live in the community, but nursing homes have a higher critical mass of very frail residents. Nursing homes today are heavily invested in short-stay, post-hospital care.

Rather than bemoan the dearth of hard evidence that HCBS is more cost effective than nursing homes, it is time to concentrate on applied research about which characteristics of HCBS work best for which goals and for whom. What are the necessary aspects of care and service to preserve health and improve or maintain function? What elements are important? What mixes of personnel, disciplines, and training are needed to deliver HCBS? Experts in management can shift their focus from how to organize efficient institutions to how to improve organizational infrastructures to deliver and monitor care in ever more decentralized settings. There is room for experimental designs within HCBS programs to test the effects of various approaches and technologies on the well-being of LTSS consumers and their families.

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debates continue over how to reduce costs without considering what's for sale. Buying undesirable and undesired services, even at a steep discount, is not prudent. Private costs also need to be considered—private resources expended and dollars spent represent a cost to our economy as well as to the individuals and families involved. Although in the last decade there have been attempts to calculate the costs of family care and of various diseases, these efforts are typically based on broad extrapolations and produce very high figures—and very few solutions.

Putting HCBS Front and Center
Moving HCBS into a prominent position as a first choice in LTSS will require addressing several issues.

Eliminate fuzzy boundaries. One must define obscure and shifting boundaries in order to put HCBS, or even LTSS, into the context of policy. The line between long-term and acute care is confused by post-acute care. Transitions are often subtle and distinctions arbitrary. Likewise, arguments over institutional and community care may have lost their relevance—as hinted at by both the Hernandez article on assisted living (page 118) and Jenkens’ and colleagues’ article on a “community-based nursing home” (page 125). It is cliché to bemoan silos in healthcare, often in the same breath as trying to more precisely distinguish between programs. We need to rethink the underlying challenges and building blocks for providing LTSS to elders, and stop conflating those with what we call the care—nursing homes, adult foster care, home healthcare, attendant care, daycare, or assisted living. We can move forward by going back to basics.

Create building blocks for LTSS for elders.
We need new modes of care that address the basic needs of frail older persons. Good long-term care requires three basic elements: personal care and support; medical care for underlying
chronic diseases that typically create the need for care; and housing. Personal care (or attendant care) includes ongoing help with a wide variety of daily living tasks and activities, both at home and in the larger community, and across a round-the-clock timetable as needed. Routine nursing care, including medication administration, is part of this personal care group of services. Medical services include the services of physicians, nurse practitioners, and physician assistants involved in primary care, and the wide array of medically related specialists for health and mental health care. This second component also requires hospital care when needed; specialized rehabilitation services, including physical, occupational, and speech therapy; palliative services for pain management; and expert care for the dying. Managing chronic disease requires close coordination with those providing daily personal care. Chronic care management requires regular, systematic observations of a patient’s status and timely interventions to avoid catastrophes (Kane, Reinhard, and Totten, 2005).

Think about new models for housing. Housing is not generally considered care, but everyone receiving LTSS needs a place to live that they can afford and is adaptable to meet their needs. Some geographic concentrations make delivering services more efficient, and offer the possibility that more care will get to the consumers at the right time. If we start from the premise that good care will combine these elements in creative ways, we open our thinking to new arrangements and move away from our preoccupation with restrictive dichotomous alternatives (i.e., either institutional care or community care). In general, we think the desired model will differ for people in their eighties, nineties (and older) than for people in their twenties, forties, or even sixties. First, there’s the likely presence of unstable and serious health conditions, and then the older old are closer to death and have different imperatives and social goals. But the desire for control, social integration, and a lifestyle of one’s choosing (so well-argued by the disability movement) holds true for all those who need LTSS.

Uncouple housing and services in institutions. A nursing home rate encompasses room and board and a range of required services. Consumers—even those whose care is entirely paid by Medicaid—do not receive that care for free; anyone drawing Social Security has to contribute their entire monthly check, minus a modest monthly personal needs allowance. But the notion remains that room and board is covered in the rate, just as is the case for hospitals. Otherwise Medicaid does not pay for room and board. People living at home and receiving HCBS waivers must be responsible for their housing and living expenses. In assisted living and other group residential settings, typically an amount is established for room and board and then the service component (beyond meals) can be covered under HCBS waivers for low-income persons. Along with others, we have argued that nursing homes should also separate room and board from services (Kane and Kane, 1991; Kane, 1995). Structured that way, the high price and general low acceptability of the housing component would make it highly unlikely that older persons would choose a nursing home—at least as we know them today. This one re-jiggering would eliminate the distinction between community and institutional care. True, it might be difficult to determine a fair price for housing and food services. But there would be many advantages to

There would be many advantages to splitting LTSS into housing and board (paid from income), and services (covered under government programs, or insurance).
splitting LTSS into housing and board (paid from income), and services (may be covered under means-tested government programs, private insurance, or universal insurance).

**Meet the challenges of widespread HCBS.**

We cannot predict what technological changes may occur in the next thirty years, but we can confidently predict there will be major changes: we may have smarter houses, smarter cars, robotic assistants, and ever better information technology for a generation of tech-savvy elders. We may conquer Alzheimer’s Disease. Even so, LTSS will remain challenging. In the short run, few elders have large savings. The people turning age 70 twenty years from now may have even less than today’s older adults in terms of home ownership, savings, and pensions.

As more extremely fragile older persons receive HCBS, we can expect to find more quality problems. Monitoring and information systems, skilled care providers, and an informed group of older adults will help ward off crises in quality. We will also need to learn how to respond to quality problems without throwing away the programs. Indeed, we can hope that the equivalent of a nursing home thirty years from now will not be a place where the consumer loses their rights of citizenship, but rather a place where a high level of technical services is amassed and available around the clock, allowing people to live on the timetable they wish, move about the larger community as they can, and enjoy sufficient space for their interests and precious memories. Under this scenario, a decision to live somewhere that provides constant care at an affordable price would not constitute an exile from the community.

Robert L. Kane, M.D., holds the Minnesota Chair in Long-Term Care and Aging, and is a professor of Health Policy and Management, University of Minnesota School of Public Health. Rosalie A. Kane, Ph.D., is a professor in the School of Public Health at University of Minnesota, Minneapolis.

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