

By Rosalie A. Kane, Guest Editor

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

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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 Halamandaris, 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 Liviertos, 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

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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

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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 Alexih 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.

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

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 residen-

tial 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 (trade-marked a Green House) in suburban Rochester, New York, Robert Jenkins 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."

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, cogni-

tive 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. 

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