



Long-Term Care Policy: Yesterday, Today and Tomorrow

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Long-term care policy has come a long way since the creation of the Senate Special Committee on Aging in the 1960s and the beginning of my gerontological career working for a Title VII nutrition program in Baltimore in the mid 1970s. In those days, the triple knot of long-term care—financing, delivery and workforce—was primarily a family affair. And although families and other unpaid caregivers continue to provide the bulk of services today, a fragmented formal system has evolved over the past 50 years to help meet the long-term care needs of our nation’s elderly population.

With the advent of Medicaid and, to a lesser extent, Medicare, a public market for nursing homes was established. From the very start, the Senate Special Committee on Aging has been vigilant in its support for resident rights and quality, including its advocacy for the development of the National Long-Term Care Ombudsman Program, Nursing Home Reform legislation in the 1987 Omnibus Budget Reconciliation Act, continuing efforts to ensure quality oversight and enforcement and the recent culture change provisions in the Affordable Care Act (ACA).

The shift towards home and community-based care can be attributed, in part, to the development of the aging network in the 1970s, culminating in the Medicaid waivers in 1981 which significantly expanded noninstitutional options, albeit tremendously variable by state. The Congregate Housing Services Act—supported by the Committee—was the first national effort to link affordable elderly housing with services. The field also experienced growth in a private assisted living market and experimentation with this residential alternative through various state-based Medicaid waiver programs. In the 1990s, elderly consumers followed the

lead of their younger disabled colleagues in advocating for more consumer-directed options, giving individuals and their families more autonomy and choice in how resources are used. From 1997 to 2009, home and community-based care spending increased at a compound annual growth rate of 11.4 percent, rising from \$13.6 billion to \$49.7 billion. The proportion of Medicaid spending for these services grew from 24.2 percent in 1997 to 43.6 percent in 2009. In contrast, the proportion of Medicaid spending for institutional care declined from 75.8 percent to 56.4 percent.

Despite the fact that most individuals needing long-term care also suffer from multiple chronic conditions that often need medical intervention, care delivery has developed in silos. One of the first programs to integrate acute, primary and long-term care services—the OnLok program in San Francisco—was initially developed through a Title IV demonstration grant for the Administration on Aging. Three decades later, the Program of All Inclusive Care for the Elderly (PACE) is a permanent Medicare provider and has set the gold standard for service integration and care coordination. Over the years the Committee has supported experimentation with a range of integrated approaches and was a strong advocate for the most recent ACA demonstrations designed to improve quality and reduce costs.

How to finance long-term care has been a key question for policymakers since the founding of the Senate Special Committee on Aging. Over the years, Medicaid has become the major public payer—for poor individuals or those who “spend down” to qualify for benefits. The Committee has participated in at least two failed long-term care financing reform efforts—the 1989 Pepper Commission proposal and a new national home and community-based care benefit proposed in the 1993 Clinton Health Care Reform proposal. A more modest legislative initiative passed in 2005--the Long Term Care Partnership--allows people who purchase

approved private long-term care insurance policies to qualify for Medicaid while retaining a higher level of assets than would otherwise be allowed. As of 2009, 36 states had adopted a program and more than 100,000 policies were in force, but a Congressional Budget Office estimate indicated that the program ultimately would cost rather than save Medicaid dollars. The Community Living Assistance Services and Supports (CLASS) program, included in the ACA, allows working people to purchase on a voluntary basis a federally administered, long-term care insurance policy providing home and community based care coverage. Recent concerns about CLASS's long-term viability have, however, put program implementation on hold and its future is uncertain.

Until 2000, the long-term care workforce was just an afterthought. The Committee was instrumental in raising this issue to a priority level. Efforts have included holding hearings following the release of the seminal IOM report—Retooling for an Aging America, and advocating for the inclusion of education and training opportunities for long-term care professional and direct care workers in the ACA. The Committee remains committed to this area as is evidenced by its ongoing work to get funding for the authorized programs.

Where Do We Go from Here?

The United States is still a relatively young country compared with most of the countries in the developed world. The aging of the baby boom generations, however, will place increasing demands on our currently fragmented system of long-term care but will also provide opportunities for growth and economic development. The three issues that loom large over the next 20 years include 1) how modes of service delivery might evolve in response to consumer preferences, ability to purchase care and changes in public policy; 2) whether and how a quality,

competent paid workforce will be developed to meet the service demand; and 3) how these services can be made affordable for the majority of older adults who are at risk for needing long-term care and for the federal and state governments that currently foot much of the bill.

While the future of long-term care policy remains uncertain, a number of demographic and service delivery trends suggest that the long-term care delivery system will look very different in 2030 from what it does today. A much larger proportion of the elderly population will be age 85 and over and likely to need long-term care (although the increase in that proportion does not reach its peak until 2040 to 2050 when all of the baby boomers have attained that age). These elderly individuals will be more highly educated than the current cohort of older adults, which will undoubtedly translate into consumer demand for a wider array of service options. The increased ethnic and cultural diversity among the future elderly population will influence further the types of services that will be required to meet the needs and preferences of diverse elderly and family caregiver subpopulations. Given the fact that baby boomers and, to a greater extent, their children--the future family caregivers--are currently much more facile with technology than their parents and grandparents, it is likely that information technology and technological devices will play a much larger role in the delivery of services and supports in 2030 than they do in today's market.

A Vision for Long-Term Care Service Delivery in 2030

It is not possible to predict how the service system will evolve. There are a number of factors at the macro and micro level that will influence the nature and scope of service delivery in the future. A change in policy, for example, could significantly affect the way services are delivered, although policy incentives do not guarantee that a new approach will be broadly

adopted and implemented. While there has been an increasing public policy emphasis on shifting resources from institutional care to home and community-based options for low-income elderly individuals, 25 years of effort has not produced the shift that might have been expected from the rhetoric on “rebalancing” the system. Similarly, demonstration activities and specific financial incentives have focused on better integration of acute, primary and long-term care services for many years, with relatively few successes in achieving this goal. Although long-term care policy and practice has come a long way since the creation of the Senate Special Committee on Aging, there are many opportunities for the Committee to influence the nature and scope of long-term care financing, delivery and workforce over the next several decades.

I am hopeful that by 2030, the Committee will have helped to make normative a more responsive and integrated long-term care system than currently exists in the United States. This system would include the following elements:

The Role of Family Caregivers

Family caregivers will probably continue to play the pivotal role in the delivery of long-term care services. To the extent, however, that it is financially feasible and preferred, they will augment their hands-on care and oversight through the purchase of home and community-based services and technology. Non-kin informal caregivers—including “significant others”, neighbors and friends—may assume more responsibilities for those individuals who lack close relatives or do not live in close proximity to family members. Technological advances—including the development of web-based social networks, sensors and electronic medication reminders--will support more long-distance caregiving, leading to an expansion of geriatric care managers and brokers to assist in these efforts. The ability of technology to complement

informal caregiving, of course, is contingent on the mitigation of the myriad barriers to development, adoption and wide-scale use.

Family caregivers will have access to more formal training than exists today, provided through an array of community-based organizations and offered through multiple modalities, including on-line. Increased demand for respite services to allow relatives to have a break from caregiving will encourage the development of more adult day health centers that are open on weekends and evenings as well as during the five-day work week. The federal Family and Medical Leave Act, that currently requires employers of a certain size to grant unpaid leave to family caregivers, may also follow the lead of states such as California that require employers to make paid leave available to employees with significant caregiver responsibilities.

The Committee has a major role to play in ensuring that family caregivers continue to receive support and that they are integrated into the long-term care decision making process. The National Family Caregiver Support Program, created in 2000, formally acknowledged family caregivers as a specific target population for education, training and other resources. To date, however, program funding has been limited. Ongoing advocacy will be required to expand the magnitude and scope of the program as well as other efforts designed to alleviate caregiver burden and burnout.

The Role of the Nursing Home

The primary role of the nursing home in 2030 will be to provide post-acute care to medically complex individuals being discharged from the hospital or those who require significant rehabilitation following such events as a stroke or post-fall hip replacement. These facilities will also provide a venue for the delivery of palliative care to individuals in the active stage of dying who are not able to remain at home or in another residential setting. Given the

preference for individuals to receive services in their own homes and/or their communities, the more traditional long-term care services needed by individuals over an extended period of time will be made available through a variety of home and community-based settings.

Home and Community-based Services in 2030

By 2030, the demand for home and community-based options, coupled with continued policy shifts away from institutional care on the part of Medicare and Medicaid, will have contributed to the development of a more robust home and community-based service system than exists today. Home-based care will be provided by a combination of in-person and electronic monitoring systems (including electronic health and long-term care records) to facilitate the potential for a larger proportion of the elderly long-term care population to receive services in their own homes or apartments. In addition, the expansion of universal design features in building construction and modifications will help to create home environments that adapt to the needs of individuals as they age and become more disabled.

Many individuals will be living in NORCs—naturally-occurring retirement communities—where at least half of the residents living in the enclave have reached age 60 and have decided to remain in their homes or apartments rather than moving to some other living environment. NORCs may be vertical--existing in apartment or condominium building--or horizontal across streets, blocks or neighborhoods of single-family homes. Regardless of the configuration, community members will take advantage of the economies of scale and joint purchasing power afforded by living in the NORC to organize a package of social, wellness, health and long-term care services that are available the entire community.

For those who can no longer remain in their own homes, some will move in with family caregivers, perhaps into granny flats attached to their children's homes or a mobile pod located

in the backyard (as was most recently encouraged through a change in zoning laws in Virginia). Those with no family and individuals who either prefer to live alone or who need a higher level of service than can be provided by relatives or other informal caregivers, will need residential alternatives that provide room and board as well as long-term care services ranging from personal care to skilled nursing. To the extent possible, these residential alternatives will be designed to mirror the home environment that the elder lived in prior to the move—including small group houses (such as the Green House model) and apartments with services. Computer-generated social networks will keep even the most disabled older adults connected to family, friends and others by creating “senior centers without walls” in which individuals can communicate, socialize and share information.

The Integration of Services

Relatively few older adults in the United States today have access to an integrated system of care that is person-centered and that brings together the preventative, primary, chronic, acute and long-term care services that most elderly individuals will need as they become older and face greater risks of illness and disability. To date, integrated models and programs have had little penetration beyond small market areas and have not become normative in terms of health and long-term care practice.

Assuming that the ACA payment reforms, demonstration and pilots are implemented and sustained, by 2030, integrated systems of care could become the norm rather than the exception—particularly for older adults and younger people with disabilities. The evolution and wide scale adoption of electronic health and wellness records by multiple delivery settings could further escalate the development of integrated care. While targeted programs such as PACE and other Medicaid managed care initiatives have only served a small proportion of high-risk,

disabled older adults, the development of broader, more inclusive programs that offer early prevention and risk management for “well elders” as well as chronic care management and long-term care for more disabled older adults have the potential to be more financially viable as the costs are spread across a larger population.

Who Will Care for Us?

In order to achieve the vision of a community-based, integrated delivery system for 2030, a well-trained, competent, quality workforce is essential. There is widespread consensus that there are insufficient numbers of competent licensed and direct care staff to manage, supervise and deliver high-quality care to the elderly population. Without decisive action in the public and private sectors to strengthen and expand this workforce, the situation is expected to worsen as the health and long-term care needs of older adults butt up against population aging. Although technological advances can help to mitigate somewhat the need for hands-on staff, the development of the kind of delivery system described above will require significant attention to and investment in the future long-term care workforce.

Some characteristics of the long-term care workforce are given in 2030. Despite attempts to attract males into this sector, long-term care will probably continue to be dominated by women, particularly the direct care workforce (90 percent female in 2008). The direct care workforce is already ethnically and racially diverse with only 49 percent being white non-Hispanic in 2008. This trend is likely to continue upward over the next 20 years. Although the racial and ethnic composition of the licensed professional staff in 2030 is less clear, there will be a need for a culturally competent staff to work with a very diverse direct care workforce and to ensure good quality interactions with a primarily white elderly clientele.

The Special Committee on Aging has a significant role to play in helping to develop sound workforce policies and ensuring that adequate investments in education and training are made to recruit and support the human capital that will be needed to address the long-term care needs of an aging America across the spectrum of settings. Growth will be greatest in the home and community-based care sector, with many opportunities to manage and provide direct care in residential settings and in individual homes and NORCs. Educational curricula in colleges and universities will address this evolution of home and community-based care options and will be preparing students to work in settings that increasingly rely on technology to assist in care delivery and coordination across providers. Retirees looking for a second career out of financial necessity or a desire to engage in a helping profession will be enrolled in educational programs to prepare them for employment in long-term care. Home care options will provide opportunities for flexible hours and job sharing to meet the needs of many older workers who do not want full-time jobs. Families and friends who are paid to deliver care through consumer-directed programs will be trained alongside other direct care workers in how to safely and effectively deliver personal care/attendant services.

Those choosing to work in nursing homes, assisted living and other residential care alternative settings will have embraced person-centered care and culture change. Managers and clinicians will come into organizations with the knowledge and competencies to create a living and work environment that places the resident and family at the center of decision making and that empowers frontline staff to play a key role in the self-managed work teams that will delivering care. Staff at all levels will receive in-service training on the latest developments in resident-centered care--particularly for people with dementia, how to use the latest iteration of information technology and devices and how to continuously engage in quality improvement. All

nursing homes will have nurse practitioners who will either serve as medical director or work with the physician in that role to ensure that the care delivered to the post-acute population with complex medical or rehabilitation needs are receiving high quality care and that they are returning to the community without the risk of rehospitalizations or other problems.

Long-term care staff will also be an integral part of integrated service teams that coordinate services with hospitals, primary care practices, clinics and other segments of the health care system. Administrators, clinical professionals and direct care staff will have the knowledge and competencies to ensure that elderly long-term care consumers with acute or chronic medical care needs receive their care in the community to the extent possible and that transitions between settings are smooth and do not result in preventable negative outcomes.

The Affordability Question

Prior to the passage of Medicare and Medicaid, one third of the elderly population lived below the poverty line. During the following three decades, that percentage decreased precipitously. At the same time, however, the gap between the “haves” and the “have nots” within the older adult group expanded, and the latest recession—which disproportionately affected current and “soon to be” retirees—raises serious concerns about how future cohorts of older adults facing long-term care decisions will be able to pay for services.

Ironically, those who are currently at either financial extreme are more likely than modest and middle income elderly individuals to have access to many service options. Low-income elderly individuals who qualify for Medicaid (either directly or by “spending down” their income and assets to become financially eligible) are entitled to nursing home coverage and—depending on the state in which they reside—may also have access to publicly subsidized home and

community-based care. They also may qualify for publicly subsidized senior housing, although the supply of this residential option is very limited. Financially secure elderly individuals have the resources to pay privately for home care, and when that no longer is a viable option, to move into an assisted living facility. Individuals who want the security of a continuum of services may sell their homes and buy into a continuing care retirement community that offers independent housing, assisted living and skilled nursing to its residents (Baldwin and Poor, 2009). Others may create their own Villages—a grassroots, membership-based, non-profit organization that provides support and community to residents who wish to remain in their own homes or apartments as they age. They are self-governing and self-supporting entities, financed by a combination of membership fees, fundraising dollars and in-kind support. Currently there are 48 fully operational Villages in the country and over 100 communities developing this model, with the first established in 2001 by the Beacon Hill Village in Boston.

For the vast majority of elderly individuals and their families, however, affordability of long-term care service options is, and will remain, the ultimate concern. There are a number of uncertainties which contribute to this concern and ambiguity about what type of system will be available and accessible in the future. First, recent state Medicaid budget cuts in response to the latest economic recession underscore the fragility of this program as a safety net for modest as well as low-income older adults who need services. Home and community-based services—the options most preferred by elderly individuals and their families--have been the most vulnerable in bad economic times.

Second, the fact that the private long-term care insurance market has not grown significantly, even among federal employees and retirees to whom a federally sponsored product has been made available suggests that this financing mechanism will not solve the affordability

dilemma for most baby boomers. The uncertain future of the CLASS provisions in the ACA—which would have provided moderate income individuals access to modest coverage for home and community-based services—underscores the role that the Committee will need to continue to play in exploring affordable financing options

One of the thorny issues that must be addressed if affordable residential options are to be available in the future is how to cover the housing costs for individuals who can no longer remain in their own homes or rental apartments due to financial and/or health reasons. Currently, low and more modest income older adults who have spent down their assets and income to qualify for Medicaid will have their room and board costs covered if they enter a nursing home. Medicaid reimbursement rates for other residential settings such as assisted living or adult foster care, however, are generally not sufficient to cover the costs of room and board. And for those who do not qualify for Medicaid, there are no financial mechanisms to help defray the housing costs. Recognizing that Medicaid assisted living programs have not proven to be an affordable community-based option, a number of states (e.g., Vermont, Oregon) have brought together staff from their Medicaid and state housing agencies to explore how they can more efficiently package their service and congregate housing dollars to better serve their dual eligible populations. At the national level, HUD and DHHS are exploring ways to better integrate low income senior housing and services.

These efforts reflect a growing recognition that affordable shelter and services are both essential to the development of viable community-based long-term care options for moderate and low-income older adults—groups that are likely to represent a large proportion of future cohorts of America’s elderly population. The nexus between housing and services, therefore, is a perfect place for the Committee to focus its attention as we move into the future.