

The Future of Long-Term Care and the Aging Network

Before concluding that proprietary organizations should provide LTC services, we should analyze the effectiveness of the existing community-based LTC system.

Our long-term-care (LTC) system should be an asset in our efforts to build strong local and regional communities for everyone, regardless of age or disability. To achieve this goal, we need to have a serious national conversation and debate about LTC policy. Such debate should include a careful review of the role and history of the aging network in the development of community-based LTC services and supports. This article describes and assesses the existing, mostly aging network-administered home- and community-based LTC system and its capacity to provide cost-effective services that promote quality of life and community integration. The concluding section focuses on the need for more rigorous evaluations that compare cost-effectiveness between the network and HMO-managed long-term services and supports (LTSS) alternatives, and for a vigorous, comprehensive discussion about the future of LTSS.

The Future of Long-Term Care: Needs, Capacities, Uncertainty

Most families at some point confront the need for LTC for older family members or younger relatives with disability. It is very difficult for families to anticipate and plan effectively for LTC needs, which are highly variable and must often be provided over a period of several years. The economic and emotional challenges asso-

ciated with caregiving can be enormous, whether the care is provided directly by family members or through paid assistance in the form of personal care, homemaker services, adult daycare, home healthcare, assisted living, or nursing home care.

These needs will increase greatly over the next few decades with the aging of the Baby Boom Generation. Of 10 million Americans who currently need LTSS, 5.2 million are ages 65 or older, and 1.71 million are ages 85 or older. These numbers are projected to double over the next thirty years. The resources required to provide even the current level of services will triple by 2040, in part due to the rapid growth of the population ages 85 or older, and the increasing longevity of younger people with physical disabilities and people with intellectual disabilities.

In addition to the rapidly growing demand for LTSS, the gap between the numbers of available family caregivers and the number of persons needing LTSS services will increase substantially between now and 2030. According to a 2013 AARP report on “caregiver support ratio,” defined as the number of potential caregivers ages 45 to 65 for each person ages 80 and older, the ratio is projected to decline to 4:1 by 2030, compared to 7:1 in 2010. The ratio is expected to further decrease to 3:1 in 2050 (Redfoot, Feinberg, and Houser, 2013).

Even as the number of people needing LTSS services grows inexorably, the capacity of individuals and families to cover out-of-pocket LTC costs will likely decline due to erosion in the economic security of retirees over the past two decades. The Center for Retirement Research estimates that the percentage of future retirees who will not be able to maintain 80 percent of their last wage in retirement will increase from about 50 percent today to more than 60 percent by 2035 (Munnell, Webb, and Golub-Sass, 2012).

The capacity to meet LTSS needs is already limited to a relatively small minority of U.S. households. AARP has found that nationally, private nursing home costs in 2012 averaged 252 percent of the median household income for those ages 65 and older, while the cost of home health services (thirty hours per week) averaged 88 percent of median income. These significant demographic and economic trends will make LTSS even less affordable in the future, and increase already high levels of dependency upon Medicaid, the principle payer for LTSS (accounting for 40 percent of the LTSS expenditure), and other sources of public support.

What we clearly and urgently need is a serious, sustained public discourse about how we can best meet the LTC needs of older and younger impaired persons. Instead, the CLASS Act, which was the first national effort to create a LTC social insurance program, has been repealed. At the same time, many state legislatures have either reduced or minimally increased funding for community-based, Medicaid-funded LTC programs since the Great Recession began in 2008.

Plus, private insurance for LTSS appears to have peaked at about 10 percent of the ages 65-and-older population, and may decline in the absence of substantial public sector support. Hoping that individuals and families will be able to shoulder more of the LTC cost burden in the future is not supported by available data on the economic resources of older or aging Americans (Polivka and Estes, 2009). It also deflects attention from the most pressing task, which is

how we can most effectively and efficiently meet the growing need for LTSS through both public and private programs.

The Aging Network and Long-Term Care

The aging network, consisting of more than 600 area agencies on aging and several thousand small- to medium-size service providers, provides services to most of those receiving publicly supported home- and community-based services (HCBS). According to an AARP survey of state LTC systems (Houser, Ujvari, and Fox-Grage, 2012), the aging network in most states largely has succeeded in creating HCBS systems of LTC, especially since the early 2000s.

The HCBS Medicaid waiver-funded programs have grown faster than any other part of the publicly funded LTC system over the last decade. This is one major reason for the decline in the nation's nursing home population from 1.7 million in 2005 to 1.6 million in 2012, and for the federal Medicaid nursing home budget's stabilization at about \$48 billion since 2006. Ten states now serve a higher percentage of their Medicaid LTSS beneficiaries in HCBS programs than in nursing homes, and spend more of their Medicaid dollars in the community than in nursing homes. Several other states are on a trajectory to achieve the same kind of balanced LTC system over the next few years, mostly under the auspices of their long-standing aging network organizations.

Is HCBS, constructed and sustained mainly by the aging network, cost-effective?

Past reviews of HCBS programs have been unable to draw definitive conclusions because of substantial variability across HCBS programs in availability, coverage of services, eligibility criteria, financing and administrative structure, and methodological limitations of past evaluations (see reviews on HCBS by Grabowski [2006] and Wysocki et al. [2012]). However, recent longitudinal studies using advanced statistical analysis techniques and diverse samples of LTSS users have reported favorable results. Findings suggest that HCBS have been beneficial in terms of improved health and functional outcomes (APS

Healthcare, 2005; Muramatsu, Yin, and Hedeker, 2010), reducing risk for institutionalization (Miller, 2011; Muramatsu et al., 2007), and lowering cost (Kaye, LaPlante, and Harrington, 2009; Shireman and Rigler, 2004).

As well, it appears that the long-feared “woodwork effect” has been largely contained in recent years. That is, states have learned how to use HCBS program expansion to contain increases in overall LTSS costs. A recent national study by Kaye and colleagues (2009) found that between 1995 and 2005, LTSS expenditure decreased by 7.9 percent in states with established HCBS programs, although the average LTSS expenditures across states grew by 7.3 percent (with a large decrease in 2003 to 2005). They note that HCBS expansion entails a short-term increase leading to a longer-term reduction in nursing home care and long-term cost-savings.

Overall, the AARP state LTC snapshot studies and the broader research literature strongly indicate that the aging network has been effective in most states in developing community-based LTSS systems that have helped reduce dependency on nursing home care and provide the less expensive home- and community-based alternatives many frail elderly persons vastly prefer.

Current long-term-care initiatives: a move toward managed LTSS administered by proprietary HMOs

The aging network has done a relatively cost-effective job of creating a HCBS infrastructure across the country over a thirty-year period. Yet arguably the most important recent initiative in LTSS policy at the national level, and in a growing number of states, is the move toward managed LTSS strategies, largely administered by proprietary HMOs. Sixteen states now administer some form of managed LTSS and several more plan to implement managed LTSS programs over the next few years. Less than 20 percent of LTSS recipients are currently enrolled in managed LTSS programs, but this percentage is set to increase rapidly.

The large states, including New York, Florida, and California, are implementing or ex-

panding managed LTSS programs over the next few years. Most of these programs are administered by proprietary HMOs, followed by private nonprofit organizations and public or quasi-public organizations (Saucier, Burwell, and Kasten, 2012). In addition, proprietary HMOs also are administering a majority of Medicare and Medicaid integration demonstration programs in the fifteen states; these are supported by a recent federal integration demonstration providing services for dually eligible beneficiaries.

The main rationale for HMO-administered managed LTSS is that by properly aligning incentives through a capitated payment system for Medicaid services, states can more efficiently substitute less expensive HCBS for nursing home care and accelerate the movement to more balanced LTSS systems. But the research literature indicates that the aging network-administered LTSS systems in several states over the last twenty-five years (largely based on the use of Medicaid HCBS waiver funds) have developed a track record in this arena. Moreover, the rationale for promoting managed care approaches to integrating Medicare and Medicaid services, and superior efficiency and effectiveness of such approaches, has not been supported by the empirical evidence.

Consider the Medicare Advantage (MA) program. Although there has been substantial growth of the MA program since 2006, studies have not found the cost-savings or better outcomes that were predicted when the program was created (Gold, 2012). Instead, most of the research shows that the MA program costs significantly more than the conventional fee-for-service Medicare program, and fails to generate consistently better healthcare outcomes (Duggan, Starc, and Vabson, 2014).

Preserving and strengthening the role of the aging network in LTSS

Discussion about the future of LTC policy and practice should, at a minimum, be informed by an analysis of the effectiveness of the long effort to build a community-based LTC system, before

concluding that other kinds of organizations, including proprietary HMOs, should be relied upon to provide these services in the future.

While the number of people needing LTSS services grows, family capacity to cover out-of-pocket LTC costs likely will decline.

The available literature indicates that properly administered state LTC systems designed to expand aging network–managed HCBS programs can achieve cost-effective outcomes, including the substantial reduction of nursing home use. Oregon and Washington were able to create the nation’s most balanced LTC systems in the early to mid-1990s by relying on strengthened aging networks that rapidly reduced nursing home use and expanded HCBS programs. Wisconsin was able to dramatically improve the quality and balance of their LTC system (APS Healthcare, 2005; Fox-Grage and Walls, 2013) by using their aging network and other public agencies to create a nonprofit-managed LTSS program called Wisconsin Family Care. In a rigorously designed evaluation, the Wisconsin Family Care Program was shown to be highly cost-effective in creating a HCBS-oriented LTSS system (APS Healthcare, 2005).

In addition to cost-effectiveness, its ability to strengthen and maintain an informal caregiving network offers another important rationale for preserving and strengthening the role of nonprofit aging network agencies in LTSS. LTSS are labor intensive and, at best, depend upon close interaction between formal (paid) and many forms of informal (unpaid) care provided by family members, friends, neighbors, and members of voluntary organizations. The social capital (community trust and support) of nonprofit organizations is essential to building and maintaining the formal-informal caregiving network. The informal network of caregivers is more likely to thrive under the leadership of nonprofit, mission-driven organizations than in for-profit organizations with a primary focus on generating shareholder value.

It may be even more important to strengthen the role of the nonprofit aging network in LTC than to maintain a nonprofit presence in the acute care system for the reasons described by Schlesinger and Gray (2006) in their comparative analysis of for-profit and nonprofit healthcare services. Unlike most of the rest of the healthcare system in the United States, much of LTSS are still administered by a large number of nonprofit organizations, most of which are part of the aging network. These organizations, with their extensive community support and high levels of volunteer participation, are a major reason community-based LTC is still reasonably affordable in most parts of the country.

Strengthening networks of formal and informal care is important to meet not only the growing need for both privately and publicly supported LTSS, but also to avoid the potential crisis of caregiving:

... the danger that some old people will be abandoned or impoverished, with no one to care for them, no advocate to stand with them, and inadequate resources to provide for themselves (The President’s Council on Bioethics, 2005).

A smaller number of potential caregivers, combined with an increasing number of baby boomers who will not have children or spouses to help provide care, suggests a growing caregiver challenge. These trends and an increasing percentage of retirees without the resources to pay for their own LTC, indicate that the frail older persons of the future will be more and more dependent upon publicly funded programs and active community involvement. Communities will be pressed to generate the levels of financing and social capital required to prevent the abandonment of older people who cannot pay for their own LTC.

This kind of LTSS system that is deeply embedded in the community could become an essential part of a more comprehensive, community-based (rather than corporate) model of integrated, person-centered care that encompass-

es all domains of care—from preventive and acute care services to LTSS. Joanne Lynn has proposed the development of what she calls a “MediCar-ing” Accountable Care Organization to serve frail elders at the community level (Lynn, 2013).

We agree that such a system of care is needed to improve the quality and efficiency of care for older people and to prepare the nation for the huge aging demographic increases over the next twenty years. In most states, the aging network organizations are essential and widely supported parts of their local communities. They are well-positioned to serve as hubs for community-based, integrated health and LTSS systems. The displacement of the aging network by HMOs would, in our judgment, represent a lost opportunity in the development of such systems of community-based and person-centered systems of care.

Need for Rigorous Research and Evidence-Based Policymaking

Affordability will become an even more critical policy priority as the years tick by, but the focus on affordability should be informed by the best available research on LTC and related issues. We need more thorough and rigorous studies that assess and compare the aging network’s capacity to provide cost-effective services, compared to HMO-managed LTC systems. This research should include more than just fiscal issues; it should also address quality-of-life issues and the need to keep elders as integrated within their communities as is possible. Without data- and research-driven systems of accountability, our ability to provide enough services of an adequate quality to a growing number of elderly and disabled people in the years ahead could be seriously compromised.

Aging network organizations in many states have been able to build relatively low-cost home and community LTSS programs over the last thirty years. According to the rationale for HMO-administered managed LTSS, however, more can be done to accelerate the expansion of

HCBS programs, reduce LTSS spending, and improve the quality of care provided through managed LTSS. These are empirical claims that can readily be tested with information generated by comprehensive and consistently implemented data systems designed to monitor services, costs, and consumer outcomes.

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Such data also could be used to address concerns raised in recent media accounts of managed LTSS (Bernstein, 2014a, 2014b). These concerns regarding the impact of managed LTSS include, but are not limited to, the impact of capitation-based incentives on access to care (i.e., whether eligibility criteria are tightened or wait lists are increased to reduce the number served); appropriateness of care provided (i.e., whether in-home and assisted living settings are appropriately substituted for nursing home care); and the quality of care received, as measured by such variables as changes in functional and physical health status, reductions in avoidable hospitalizations, more integrated transitions, and greater consumer satisfaction. To address these questions, measures in these important areas should be designed to build upon and extend the performance measures now included in the Healthcare Effectiveness and Data Information Set (HEDIS) report required annually from managed care plans in the MA program. Effectiveness measures for LTSS are still very much a work in progress, but with the growth of managed care models and the kinds of concerns and questions described and raised above, we can expect this work to accelerate, especially as the Medicare-Medicaid integration demonstration projects come online.

The already wide range of LTSS systems across the country offers extraordinary opportunities for the comparative analysis. Consider the comparisons between alternative models from

largely fee-for-service aging network–administered systems (Oregon, Washington, and Vermont); a largely HMO-administered managed LTSS system (Arizona, New Mexico, Tennessee, Florida, Texas); other so-called mixed models with strong elements of both strategies (Massachusetts, Minnesota, Ohio, and Michigan); and the unique Wisconsin Family Care Program, a managed LTSS program administered by aging network and related public agencies. Analyses of these different systems, based on a relatively uniform set of cost and outcome measures, could give the public and policy makers the kind of quantitative information necessary to make policy choices that are cost-effective for taxpayers, LTSS recipients, and their families.

Time to Make LTSS a National Priority

We need a serious, fully engaged conversation about what we want from our LTSS system. Such a conversation could be guided by a far more extensive and clearly defined moral vision for LTSS policy and practice than we have now—a moral vision that takes seriously the warning from the President’s Council on Bioethics (2005) that we are at risk of abandoning a growing number of non-affluent elderly and disabled persons who will need LTSS services as the older population grows.

We need to have this discussion and debate about the role of the aging network in the future of the United States LTSS system before we are

so far down the road to an HMO-controlled system that we lose the option of expanding the aging network role. The aging network has played a pivotal part in the development of LTSS systems in most states since the 1970s. This achievement has earned the network the right to be an essential part of the conversations we now need about the future of LTSS.

Such talks should be held before the aging network becomes so marginalized that it is no longer a significant LTSS player and its purview is limited to Older Americans Act (OAA) programs. OAA programs are very important and provide essential and highly cost-effective services to millions of older people (Thomas and Mor, 2012, 2013), but the heart of the publicly funded United States LTSS system increasingly relies upon the lifeblood of Medicaid funding. If the aging network is gradually excluded from the Medicaid-supported LTSS programs, one of the last bastions of community-embedded nonprofit social and healthcare may be lost to the likely detriment of both taxpayers and those who depend upon publicly supported LTSS. 

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