

# Long-term Services and Supports (LTSS): A Growing Challenge for an Aging America

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## Introduction

Most of us do not think about performing the everyday tasks of living, nor can we even imagine ourselves with a disability. But for 11 million older adults, assistance with tasks of daily living such as dressing, bathing, house-keeping, and shopping have become a part of their life (Freedman & Spillman, 2014). Since the majority of Americans do not anticipate the need for long-term services and supports (LTSS), most of us are not prepared financially, psychologically, environmentally, or socially for a long-term disability. Yet as we advance in age, the likelihood that we will experience a moderate or severe disability requiring assistance increases. For example, the proportion of older people with one activity limitation who report receiving assistance increases from less than 16% for individuals aged 65–69 to more than 75% for the population aged 90 years and older (Freedman & Spillman, 2014). Because most Americans do not plan for the likelihood that we will need formal assistance because of a disability, many of us (almost 2.1 million people over the age of 65 in 2010) (Medicaid and CHIP Payment and Access Commission [MACPAC], 2014) end up using the public assistance Medicaid program as the safety net for LTSS. With Medicaid approaching one-quarter of the typical state's budget, reliance on Medicaid has become

an increasingly challenging issue for states. As the older population with disabilities increases—projected to more than double between now and 2040—today's challenges will become tomorrow's crisis unless as a nation we plan and prepare for the potential changes.

## Trouble Spots in the Current System

In the last 25 years, the United States has made significant progress in reforming the LTSS system. The major criticisms of the past such as a lack of community-based alternatives, perverse public financing incentives, unsafe and substandard nursing home care, and a lack of data to assess quality have received considerable attention and resources. Despite good progress, the system is not where it needs to be. Given the demographic challenges of the future, the road forward may be even more difficult than the path already travelled.

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## LTSS Coverage Gap

We have made considerable strides in creating a more balanced system of LTSS funded by the Medicaid program. A number of states have done what was literally unthinkable even a decade ago: spending more money on home- and community-based services than institutional care (Eiken et al., 2014). Despite this progress, we still have a major mismatch in our delivery system. Most of our federal and state spending on LTSS is allocated to very low-income elders with severe disability who receive assistance through the Medicaid program. However, only about 10% of older adults living in the community receive Medicaid and have access to Medicaid-funded home- and community-based services. On the other hand, 2/3 of older adults in nursing homes receive Medicaid assistance (Hagen, 2013). Research has demonstrated that states that have developed a more extensive network of government-funded supportive services experience lower rates of institutionalization (Hahn, Thomas, Hyer, Andel, & Meng, 2011; Mitchell, Salmon, Polivka, & Soberon-Ferrer, 2006; Mor et al., 2007; Muramatsu et al., 2007; Pande, Laditka, Laditka, & Davis, 2007; Thomas, 2014; Thomas, Keohane, & Mor, 2014; Thomas & Mor, 2012, 2013). However, for those who do not qualify for Medicaid and given that only 7%–8% of older Americans obtain long-term care (LTC) insurance (Freundlich, 2014), the majority of expenditures on these community-based supportive services is paid for out-of-pocket by older adults and their families. When personal resources are exhausted (and in many cases become so after an older adult experiences a long-term disability), they must rely on the government-funded system for support (Wiener, Anderson, Khatutsky, Kaganova, & O’Keeffe, 2013). Creating greater and more affordable access to supports for Americans who have moderate resources and severe or moderate levels of disability is the missing link in the current system.

## Caregiving Assistance

It is estimated that informal caregivers voluntarily provide *three quarters* of all long-term care to elderly friends and family members. In 2009, the unpaid care that was provided by 42 million family caregivers was valued at approximately \$450 billion dollars (Feinberg, Reinhard, Houser, & Choula, 2011). However, the configuration of the modern family has made caregiving an ever more challenging activity. In addition, family caregivers are no longer solely assisting in instrumental activities of daily living (preparing meals and paying bills) and activities of daily living (helping to bathe and feed); rather, many are providing complex medical care to their older loved ones (Reinhard, Levine, & Samis, 2012). A survey of family caregivers found that almost half (46%)

of all informal caregivers were performing medical/nursing tasks for family members with multiple chronic physical and cognitive conditions. These tasks included things like assisting with medications, helping with assistive devices, providing wound care, helping with toilet use and incontinence care, and assisting with medical equipment. In addition, many caregivers performing these complex tasks report teaching themselves how to care for their loved ones. Family caregivers are a critical element of community living for many older adults; and despite the fact that these caregivers shoulder the bulk of LTSS, our support for caregivers is extremely limited.

## Technology

The technological innovations that have occurred in the last two decades have been remarkable. Technology to detect falls, monitor an individual’s medical condition, monitor a person’s day-to-day activities, and assess mobility patterns in the home have already become part of daily life. New developments, such as self-driving vehicles and the personal assistant robots, are being researched and tested. How can these technologies be used to help older people remain independent and to enhance their quality of living? Although there has been extensive research on the development of new technology, applied studies focusing on how such innovations can and will be used by older people has been limited. In particular, understanding how older people with disability and their families can use technological advances has received little attention. As the older population with disability doubles over the next 25 years and there are fewer family members to provide needed support, technological assistance through robotics, monitoring devices, and adaptive aids could represent an important element of our efforts to enhance and maintain independence for this growing population.

## Quality Measurement

It is critical that we enhance the quality and efficiency of the current system of LTSS. Research on quality and efficiency of LTSS has been difficult to conduct, in part because quality has been challenging to define and measure. But if we are to create an efficient and effective system, better research is critical. We do have some good examples of research that have been used to assess and improve programs and policies. For example, research findings from the National Cash and Counseling Demonstration found major improvements in quality of life and lower rates of nursing home utilization for individuals who participated in self-direction of their care (Carlson, Foster, Dale, & Brown, 2007; Simon-Rusinowitz, Loughlin, Ruben,

Garcia, & Mahoney, 2010). Using this work, the majority of states have designed self-directed programs to enhance the LTSS delivery system (Sciegaj et al., 2014). Despite some success, there is still much we do not know about how best to deliver LTSS in a variety of potential settings. Efforts to innovate, which are critical to developing the system of the future, face challenges of research lag, where the research falls behind the new program innovation. As an example, many states currently are allocating resources to integrate acute and LTSS for older people with disabilities (Musumeci, 2014). The dual demonstrations are attractive to states because of concerns about quality problems between the acute and long-term systems and because of the high cost of care for these individuals. However, the research behind the outcomes of these interventions is quite limited. Making sure that the research keeps up with rapid policy changes in health and LTSS is a growing challenge.

### Workforce

Workforce challenges continue to plague the LTSS industry. Turnover rates remain high, recruitment and retention rates remain abysmally low, and concerns about the quality of workers and the quality of the work environment have been consistent. Compounding these issues, we face a dramatic shortage of direct care workers in the coming years with the demand for these positions expected to increase by 70% between 2010 and 2020 (Paraprofessional Healthcare Institute, 2013). However, the number of direct care workers providing LTSS is only projected to increase by 20%. Innovative work in the LTSS quality arena consistently indicates that a quality workforce is the critical determinant of a successful consumer experience.

### Financing and Responsibility

Our nation's long-running debate surrounding the Affordable Care Act is a prime example of our lack of consensus on the question of individual versus governmental financial responsibility for health care. Our lack of agreement about how to finance LTSS may be even more complex than the acute health care challenges. In health care, there is a large employer presence and an agreement that older retirees should have access to health care through Medicare. Thus, the argument surrounding the Affordable Care Act (ACA), while critical and intense, focused on the 15%–20% of the population without any or adequate insurance coverage. However, in the LTSS arena, more than 90% of the U.S. population does not have LTSS coverage until such time as they have depleted their assets and become eligible for Medicaid. There

is so little consensus on this topic that the Bi-Partisan Commission on Long-Term Care could not agree to make *any* financing recommendations in their 2013 report to Congress. With no employer coverage, a limited private market, and no social insurance, combined with limited savings and access to pension plans, the vast majority of Americans are woefully unprepared financially for a disability in later life. The irony of LTSS is that the American spirit of individual responsibility is eroded for older people with disability, as two-thirds of nursing home residents die as impoverished Americans.

### Recommendations to Address Problem Areas

A quote attributed to Winston Churchill appears applicable to U.S. policy related to LTSS: “You can always count on Americans to do the right thing - after they have tried everything else.” Historically, the United States developed a paradoxical system that required individuals and families to be almost completely responsible for coverage, relied on a public assistance approach that only could be used after an individual had become impoverished, emphasized institutional care over in-home services regardless of consumer choice, created a system that emphasized professional decision-making over consumer wants, and focused on immediate, rather than long-term decisions for individuals and society. We offer six recommendations to address these long-standing challenges.

#### Ensure the Availability of Supportive Services and Programming

The Older Americans Act (OAA) is the major vehicle for the organization and delivery of social and nutrition services to older adults and their caregivers. Employing a network of aging service providers to deliver evidence-based programming, the OAA promotes independence and preserves dignity for older Americans. While Medicaid has been successful in rebalancing its distribution of services to become the largest program delivering community-based in-home supportive care, its services are only available for very low-income, severely disabled individuals. Because the OAA supportive services are not means tested and are available to individuals aged 60 years and older who demonstrate need, they provide a safety net for older adults who require assistance but do not qualify for Medicaid benefits. Previous research has suggested that increasing access and utilization of OAA services, particularly personal care services (Thomas, 2014) and home delivered meals (Thomas & Mor, 2012, 2013), offers the potential to provide real savings to state Medicaid programs by keeping dually

eligible low care residents out of nursing homes. Under the current system, a high proportion of older people with disability end up on Medicaid. With the doubling of the older population with disability over the next 25 years, it will be critical to develop a system that helps individuals live independently without solely relying on Medicaid assistance. Therefore, expanding services and carefully targeting these services has the potential to result in savings, particularly if we can prevent this group from spending down and becoming Medicaid-eligible. We recommend that a conversation and investigation take place to determine who benefits from these programs and which services are leading the way in providing community-based supports that both help caregivers and allow older adults to remain in their homes. With this information, the Administration and Congress can understand the significance and reach of supportive services for older adults and work to supplement and sustain proven and effective programs.

### Increase the Availability of Caregiver Supports and Training

With unpaid, informal caregivers playing a vital role in maintenance of community living for older adults and thereby reducing reliance on state Medicaid programs, we need to have a national focus on insuring that caregivers receive the adequate supports necessary to continue to provide the significant majority of LTSS. Caregiver stress has been identified as an important predictor of a care recipient's nursing home placement (Spillman & Long, 2009) and an important independent risk factor for caregiver morbidity and mortality (Fredman, Cauley, Hochberg, Ensrud, & Doros, 2010; Schulz & Beach, 1999). Therefore, we need to make supports available to reduce caregiver stress and caregiver burden. In addition, caregivers surveyed about their caregiving duties suggest that access to training would greatly help to allow them to continue to confidently care for their older loved one (Feinberg et al., 2011). If the health care system is going to continue to rely on these unpaid, untrained caregivers to provide more complex care to older adults needing LTSS, adequate supports and training must be made available.

The amount of resources allocated to caregiver support is quite limited. Although the National Family Caregiver Support Program was added to the OAA, these funds represent a fraction of LTSS expenditures. For older people with disability, families are a critical element in helping individuals to maintain independence. Providing adequate resources that are designed to support and not supplant family efforts will be one of the most important program design components faced over the next decades.

### Work to Enhance the Effectiveness of Evidence-Based Technology-Enabled Care

Older Americans have expressed a strong preference for remaining as independent as possible for as long as possible. The proliferation of technologies designed to help people age in place presents a tremendous opportunity to meet this goal (Cheek, Nikpour, & Nowlin, 2005). Improved public support for such initiatives can be achieved in two ways. First, an expansion of research and development funds is needed to assist University and research units in collaboration with community organizations working with older people and businesses to develop practical and usable products. Innovations that allow individuals with disability to remain at home independently can have a considerable impact on the future care and budgetary challenges faced in this arena. Such research should not only focus on the effectiveness and cost of the technology but should also include an understanding of the impact on privacy and potential ethical concerns that are pertinent to the older adult population.

Second, it is critical to explore the policy and reimbursement implications for the development of new technology. Reimbursement for telehealth care provides a good example of the challenges and opportunities facing a new technology. The idea that a nurse could reduce the number of in-person visits to an individual's home to monitor such areas as blood pressure, skin breakdown, wounds, or other conditions by utilizing telehealth care could lower costs while potentially increasing the number of patient/provider contacts. However, there are various rules and regulations for determining what is covered, where it is covered, and what delivery models are permitted. To further complicate this, the health care payers (e.g., Medicaid, Medicare, and private insurance companies) each have their own set of regulations and policies. As more technologies emerge to aid or enhance care-delivery for older adults, we are likely to see these regulatory and reimbursement systems become even more complex. Therefore, we first must conduct more research and secure field evidence that demonstrates the effectiveness of new technologies and approaches to caring. This evidence can then be used to continue to encourage the Centers for Medicare & Medicaid Services and state legislatures to revise their policies to accommodate rigorously tested, evidence-based technologies. Given the probability that many of these technologies have the potential to improve care and reduce excess expenditures, we recommend systematic evaluations of new health care-related technologies and the development of ongoing funding mechanisms for those proven to be ethical, effective, and safe.

## Expand Efforts to Measure Quality and Outcomes in LTSS

As the nation shifts toward promoting and funding evidence-based LTSS, we need to have a better way to measure and analyze the quality and outcomes associated with receipt of services. It is important that we go beyond simply measuring descriptive performance, such as the number of participants in different programs, the amount of services received, and individual and program costs. Rather, we should find ways to measure and systematically collect information on adequacy and appropriateness of care and the consumers' level of integration, control, participation, and general well-being.

Our current LTSS system is driven by health, functional, and health care-related outcomes. Outcome measures that may be appropriate and attractive to payers and policy makers include: (a) health status, including mental health and functional abilities; (b) injuries or secondary health conditions typically experienced by LTSS recipients, such as falls; (c) maintenance of community living (i.e., avoidance of institutionalization); (d) health care utilization, including avoidable hospitalization and emergency room visits; and (e) mortality. It is essential that we also assess the impact of LTSS on "quality of life" (e.g., comfort, meaningful activity, relationships, enjoyment, dignity, autonomy, privacy, individuality, spiritual well-being, and functional competence) (Kane, 2001) as well as its ability to promote a sense of safety, security, and order. Finally, a critical arm of LTSS is the benefit it has to family members and family caregivers. Outcome measures that assess caregiving-related emotional stresses, caregiver physical injuries, and caregiving-related financial stresses are also ways to quantify and provide evidence of LTSS quality and outcomes.

Measuring these factors will become increasingly important in states transferring LTSS to managed care organizations. Because managed LTSS (MLTSS) arrangements are very diverse (e.g., including several subpopulation groups, a variety of contractors, different levels of integration, and different payment models), we should ensure that various state MLTSS programs are being evaluated and that their progress is given careful consideration so that we can make informed decisions. In the absence of a set of national LTSS performance measures, states have developed their own unique approach to measuring quality in MLTSS, in effect making it difficult to identify a clear path towards comparing the quality of LTSS across MLTSS programs. Therefore, a uniform way to collect this information, measure, and compare states' performance and their different types of delivery systems is warranted.

There is no reason to reinvent the wheel. In many cases, validated instruments and measures of the needed concepts (e.g., health, health care utilization, quality of life, caregiver

burden) already exist. One possible approach is to gather LTSS outcomes and quality measurement tools from (a) states doing this type of work, (b) the research literature, and (c) national projects to improve LTSS quality and outcomes. There is a wealth of existing instruments that can be used, and by filling gaps as needed, we can identify a set of appropriate measures to evaluate the quality and outcomes of LTSS.

Regulations have already been put in place for LTSS to require evidence-based programming. The Federal FY-2012 Congressional appropriations law, for the first time, required that Disease Prevention and Health Promotion programs funded under Title IIID of the OAA must be evidence-based. Beginning FY 2016, even more strict requirements will be used to determine if a program is "evidence-based." As we are likely to continue to see required evidence in budget requests, program plans, and funding requirements, it is important that the Administration continue to offer trainings to agencies and departments in the best ways to evaluate their programs. We also recommend that LTSS providers begin to consider how they can conduct outcomes and impact evaluations to ensure that they are meeting their target goals and solidify their place in the delivery of LTSS.

## Focus on Workforce Development

We recommend that an investment be made in workforce development to promote a stable and sizeable LTSS workforce of appropriately skilled workers to meet the growing demand. Direct care positions are plagued by low wages and poor benefits: in 2012, the median hourly wage for all direct care workers was \$10.63 (significantly less than the median wage for all U.S. workers of \$16.71) and a quarter of nursing home workers and more than a third of aides working in agency-based home care lacked health coverage (Paraprofessional Healthcare Institute, 2013). These low wages and lack of health care coverage among the paraprofessional direct care workforce are particularly problematic given their level of responsibility, heavy workloads, and high injury rates (Petterson & Lawder, 2011).

While increasing the wages and benefits of direct care workers will help providers compete with other organizations to fill the demand for workers, third party payers such as Medicaid and Medicaid have to incorporate these increasing costs into their payment schedule. However, these government programs have been slow to recognize the increasing demand for direct care workers (Paraprofessional Healthcare Institute, 2001). Our recommendation is that the Administration, Congress, and the States, along with the long-term care organizations, continue to work together to improve wages, salaries, pensions, and health care benefit packages in order to increase recruitment and retention of direct care workers.

Despite the importance of increased wages and benefits, the structure of the work environment and the training and support provided for workers has also proven to be critical. Worker performance and turnover rates vary dramatically even within the same labor market, suggesting that management approaches are also critical to worker quality and success. Additional evidence-based practice on worker training, supervision, and job performance is critical. Even if wages and benefits increase, there will always be an array of issues that will be important to ensure a quality workforce. Therefore, we also recommend that efforts to improve training, establish federal certification requirements, and increase career advancement opportunities for the direct care workforce are supported.

### Considering a Combination Solution for LTSS Financing

The divide on the financing solution represents the age-old ongoing national debate about private sector versus public solutions. While we could review the positions of both perspectives, it appears unlikely that either group will acquiesce to the other. It is our contention that the challenges faced in the LTSS financing arena over the next 30–40 years are so great that the solution will require an improved recognition of individual responsibility, an enhanced and responsible private sector involvement, and a clear financing and regulatory role of the Federal and State government. Ironically, the recently repealed Community Living Assistance Services and Supports Act (CLASS), a component of the Affordable Care Act, was an attempt to accomplish this merging of responsibilities. In our belief, CLASS was included in the ACA for the wrong reason—because it helped the short-term bottom line of the ACA—and it was repealed for the wrong reason—because it was not adequately funded. However, it represented an attempt to get individuals to prepare for their own long-term needs in the context of a national program. Just as the private sector has become heavily involved in Medigap policies and now Medicare Advantage, supplemental policies would have likely flourished under the CLASS strategy. The rationale for repeal was an expectation that the approach would not collect enough in premiums to cover benefits; however, this ignored the fact that Medicaid already supports almost two-thirds of today's nursing home residents. Public dollars could be used to support Medicaid, or they could have been used to support an insurance program for some of those same people. Individuals relying on Medicaid typically have not made the investment in a long-term care insurance policy, nor are there private sector opportunities to develop a supplemental policy outside of the limited Public Private Partnership policies. Although CLASS is behind us, if we are to successfully respond to the

LTSS financing challenges ahead, a revamped combination solution will be necessary.

### Conclusion

The LTSS challenges of an aging America are indeed serious. Our overall recommendation is that we press for a full discussion about the kind of LTSS system that we will all have to access to at some point, and how we can best, most cost effectively, achieve it. In summary, the breadth and depth of issues surrounding LTSS, the number of individuals and families that will need LTSS both now and in the future, and the implications that this system will have on private and public resources suggests that the White House Conference on Aging, the Public, the Administration, and Congress must devote significant thought and action to ensure that we have a sustainable, effective, and high-quality system of LTSS.

**Our overall recommendation is that we press for a full discussion about the kind of LTSS system that we will all have to access to at some point, and how we can best, most cost effectively, achieve it.**

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