

Commentary

## Long-term services and supports in the community: Toward a research agenda

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### Abstract

Researchers, policy experts, and advocates participating in an invitational conference discussed research needed to address pressing policy issues in long-term services and supports (LTSS). Future research on need for LTSS should focus on projections of need, geographic variations, equity, and unmet needs of consumers and caregivers. Research on access to home- and community-based services (HCBS) should address progress in rebalancing LTSS in favor of HCBS, cost-containment strategies, the shift to managed LTSS, and the performance of managed care organizations. Major gaps in research on LTSS costs and quality center on both comparative costs and cost-effectiveness of HCBS versus institutional programs, cost savings of managed LTSS versus fee-for-service, performance incentives in managed LTSS, and LTSS quality and outcome measurement. Research on workers and caregivers could focus on worker availability, improving job quality, worker training standards, the impact of paying family members to provide LTSS, and the private-pay LTSS workforce. © 2015 Elsevier Inc. All rights reserved.

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*Long-term services and supports (LTSS)* comprise the personal assistance, technology, and health care-related services needed by people who are unable to perform routine daily activities without assistance. National surveys indicate that as many as 12 million Americans get help from others in either activities of daily living (ADLs, such as bathing, dressing, and eating) or instrumental activities of daily living (IADLs, such as preparing meals, shopping, and managing money).<sup>1</sup> LTSS can be provided in nursing homes and other institutional settings or in community settings, such as private homes, group homes, and assisted living facilities. The vast majority of those needing LTSS live in the community (about 10 million people), and roughly half are under age 65.<sup>1</sup> LTSS received in the person's home, a day health or activity center, or some other non-institutional setting are often known as *home- and community-based services (HCBS)*, especially when those services are provided through government programs.

Despite increasing attention to LTSS research, there remain major gaps in knowledge about the need for LTSS; access to HCBS programs; LTSS costs, quality, and outcomes; and the workforce providing HCBS. To identify gaps in knowledge about LTSS, as well as research needed to fill those gaps, the Center for Personal Assistance Services at the University of California San Francisco convened an invitational conference in September 2012. Focusing in particular on LTSS provided in community settings, the conference was attended by 36 high-level representatives of academic research centers, federal agencies, private policy organizations, and advocacy groups. This article presents a synopsis of both the material presented at the conference and the views of conference attendees as to the important issues in community-based LTSS that have not been adequately studied or understood.

### The need for LTSS

Of the approximately 10 million community residents getting help in any ADL or IADL activity, a subset of about 3 million get help with 2 or more activities of daily living (ADL), which is often the level at which individuals may be eligible for institutional care.<sup>1</sup> The vast majority (90 percent) get help from family and friends, and less than

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one-quarter (23 percent) use paid help. Young adults with 2 or more ADL needs are most likely to receive help primarily from parents, older working-age adults are most likely to receive help from spouses, and elderly adults from daughters or sons.<sup>1</sup>

A critical issue for policy and program planning is the projected need for LTSS. Projections depend partly on recent trends in the need for LTSS. Among elderly adults, several studies report a declining trend in the proportion needing LTSS, particularly during the 1980s and 90s,<sup>2–5</sup> with a few indicating a continued downward trend after 2000.<sup>6,7</sup> Among the non-elderly, in contrast, the rate of need for LTSS appears to have been increasing.<sup>8</sup> More recently, however, rates of the need for LTSS among both elderly and non-elderly adults appear to have leveled off.<sup>9–11</sup> With the aging of the population, differing assumptions about future age-specific rates of need for LTSS among the elderly and near-elderly generate large uncertainties in the projected number of people needing LTSS.

The proportion of the population needing personal assistance varies tremendously from place to place: Among working-age adults, for example, the highest rate of ADL difficulty (6.7 percent), found in part of Detroit, is nearly 50 times the prevalence of ADL difficulty in certain suburbs of Washington, DC (0.14 percent).<sup>12</sup> Geographic variation in the need for LTSS is only beginning to be understood, largely in terms of socioeconomic characteristics of the local populations. In particular, the relationship between low educational attainment and low employment in a community, on the one hand, and high rates of need for LTSS, on the other, is particularly striking.<sup>13</sup> Further study is needed on these variations.

States with high levels of LTSS need often have the smallest HCBS programs. Equity in access to and quality of services across geographical areas is another important issue for research, whether disparities relate to differences in state policies and programs, to socioeconomic conditions, or to differences between urban versus rural settings. Aside from place of residence, equity across racial/ethnic groups, age groups, settings, and disability groups should also be more closely examined. Disparities might result from distinct public programs that target, for example, people with intellectual or developmental disabilities versus non-elderly people with physical disability versus elderly people. Or they might reflect differing needs of people in different disability categories.

Certain specific populations needing LTSS have been understudied. In general, the younger the age group, the greater the deficit in research. Despite a reported quadrupling of the rate of disability among children since 1960,<sup>14</sup> relatively little is known about children needing LTSS, especially those with physical or mental health disabilities. Youth in transition to adulthood, a time when many “age out” of benefit programs offering LTSS<sup>15</sup> and may be leaving school and looking for work, are of particular policy interest, but the nature and extent of their LTSS

needs have not been extensively studied. For working-age adults, more research is needed as to how the LTSS system can best support people interesting in working.

A major barrier to research on community living is the lack of routine population-based data collection on unmet need for LTSS, covering people of all ages with all types of disabilities and including people who do and do not participate in public LTSS programs. In the mid-1990s, the last time such a national survey was conducted, about 21 percent of people needing some type of personal assistance had unmet needs.<sup>16</sup> It is likely that the expansion of government HCBS programs since then has partly filled this gap, but the lack of routine data collection on unmet need is a major obstacle to evaluating the impact of that expansion. HCBS expenditures vary considerably from state to state<sup>17</sup> and over time,<sup>18</sup> and annual population surveys measuring unmet need at the state level would shed light on the extent to which the evolving LTSS system meets people’s need for services.

A related area of research is the unmet needs of family caregivers and how public policy can best address those needs. Such research could focus not only on the impacts of caregiving on the family member (stress and physical strain, foregone employment, reduced social participation), but also on the impact of the caregiver’s unmet needs on the consumer. Some states allow payment of family caregivers through Medicaid HCBS programs, and the impact of such payments in meeting the needs of both the caregiver and the consumer have not been sufficiently studied.

### Access to HCBS

Over the past three decades, major efforts have been undertaken by many states and the Centers for Medicare and Medicaid Services (CMS) to expand access to Medicaid HCBS to meet the growing demand for services. These efforts were redoubled after the Supreme Court decision in the *Olmstead* case (*Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581 (1999)), which held that individuals have the right to live in the community rather than in institutions if they are able to do so. In 2010, the Patient Protection and Affordable Care Act (ACA) included a number of new provisions that give states additional incentives to expand and improve their HCBS programs.

Medicaid HCBS programs serve more than 3.2 million people,<sup>19</sup> a relatively small fraction of the population needing personal assistance, most of whom rely on unpaid help. Medicaid HCBS is provided primarily through three programs: HCBS (or 1915(c)) waivers, providing extensive services to narrowly defined, high-need populations; personal care services programs, offered in most states to a broad population needing assistance with daily activities; and home health, a primarily medical benefit that can also include personal assistance. Although institutional spending continues to represent the majority of Medicaid LTSS expenditures, the proportion of expenditures going

to HCBS rose from 30 percent in 1999 to 45 percent in 2010.

As a consequence of state-to-state differences in policies related to HCBS expansion and the reigning in of institutional expenditures, variation in HCBS expenditures across states remains substantial. The most recent (2012) estimates range from 27 percent of LTSS expenditures going to HCBS in Mississippi and New Jersey to 78 percent in Oregon,<sup>17</sup> which has long been a leader in deinstitutionalization. The shift of expenditures from institutional services to HCBS is known as *rebalancing*, and it is crucial to track states' progress in rebalancing their LTSS systems, as well as the extent to which HCBS systems are streamlined through taking advantage of new HCBS options contained in the ACA.

Despite improvements in access to HCBS, at least 38 states have HCBS waivers with insufficient "slots" to meet demand. Roughly half a million individuals are on waiting lists for services,<sup>20</sup> suggesting that there is substantial unmet need for services. One recent study, for example, found that longer waiting lists for waiver programs dramatically increased nursing home admissions for at-risk consumers.<sup>21</sup> Research is needed on how states manage (or fail to manage) waiting lists, and the consequences of delayed services in terms of health status, hospitalization, and nursing home utilization. Other HCBS programs limit expenditures by capping the amount of services an individual can receive; such cost-containment strategies must also be tracked and their impact understood.

Many states are moving toward offering LTSS through managed care plans that integrate acute care along with both HCBS and institutional services. Several states have recently converted all or part of their Medicaid LTSS systems to managed care, while others are participating in CMS-supported demonstration projects to move people covered under both Medicare and Medicaid ("dual-eligibles") into a managed care model. The intention is to remove silos of care, streamline the system, and, in the process, reduce costs, but there are also many potential pitfalls in the transition to managed LTSS. These include possible reductions in service hours or quality in an attempt by the managed care plans to limit expenditures and the further medicalization of services that are not always directly related to health but also contribute to social participation and inclusion.

Because of the rapid pace with which new programs are being implemented, there is a pressing need to address how CMS, the states, and advocacy organizations should go about monitoring managed LTSS plans and services, as well as the transition of individuals from traditional fee-for-service programs to managed care. As states move from fee-for-service into managed care, researchers and policy makers are in danger of losing the ability to track essential program statistics, despite a commitment by CMS to improve data collection on LTSS. Such information is essential both to hold managed care organizations (MCOs)

accountable and to properly evaluate the success or failure of the demonstrations.

Issues of how to maintain consumer-directed services and continue to ensure access to non-medical services (i.e., personal assistance not related to maintaining health) in the transition to managed LTSS are paramount. Managed care organizations typically have little experience providing either consumer-directed or non-medical services. Research is needed on ways of preserving such services in the medical-model context of a managed care organization, and there is a need to include these types of services in outcome measures. One particular non-medical service is employment supports, to facilitate both employment of the consumer, when appropriate, and continued employment of family caregivers.

### Costs and quality of LTSS

Resistance to rebalancing a state's LTSS system often arises out of a concern over increased costs. Policy makers in states offering minimal HCBS, having effectively rationed services by offering them only in a setting few people voluntarily enter, fear that large numbers of people not currently receiving services will apply for services once they become available outside of institutions. While it is clear that Medicaid HCBS programs serve many more people than would be enrolled if institutional services were the only option, spending on each participant is less.<sup>22</sup> The issue is whether the extra participants, whose needs might have gone unmet in an institutional-only systems, cause aggregate program costs to exceed those for an LTSS system dominated by institutional services.

Two recent studies of trends in state LTSS expenditures explored the question of comparative costs of institutional and HCBS programs. One found that the more rebalanced states (those with a high proportion of LTSS expenditures devoted to HCBS) spent no more on LTSS than other states, and that states with a high and steady level of HCBS spending saved money on LTSS over time, compared to states with low HCBS spending.<sup>18</sup> A second study found that gradual rebalancing over time saves money compared to a steady state.<sup>23</sup> Future studies could focus on expenditures more broadly, including hospitalizations and other acute care costs, Medicare expenditures, and the financial impact on the family in terms of lost employment of caregivers or the consumer. Or researchers could perform true cost-effectiveness studies, in which both expenditures and outcome measures are incorporated into the analysis.

Another important cost comparison relates to the anticipated cost savings of managed LTSS compared to fee-for-service systems, as well as the cost-effectiveness of the managed care model. Because the transition to managed care is fueled partly by a belief that integration of services will save money, research is needed on whether expenditures are reduced and how any savings are achieved, such as through care coordination that reduces utilization of

more expensive services. Researchers also might identify ways in which states can effectively offer performance incentives to managed care organizations to improve services.

Comparisons across care models or programs would be facilitated through the development of a robust and relevant set of quality and outcome measures, which would assess characteristics of the LTSS system, the services received by the consumer and the outcomes he or she experiences, and the caregivers, workers, technology, and resources that provide or facilitate provision of LTSS. Such measures are needed at the state, program, managed care plan, and individual levels. Program- and individual-level measures are particularly useful for identifying inequities in the provision of LTSS across disability populations, age groups, and racial and ethnic groups. Measures should include domains of community integration and social participation, as well as social and psychological support, with outcomes that are relevant to consumers and their families and allow for different individual goals, capabilities, and circumstances. There are ongoing national efforts to develop and validate outcome measures for LTSS,<sup>24–26</sup> but these may not be ready in time to help states monitor the transition to managed LTSS and keep managed care organizations accountable. Another important use for outcome measures is rating the performance of the states in delivering LTSS, an area of research that is already ongoing.<sup>27</sup>

### Workers and caregivers

Increasing access to LTSS and improving quality is predicated on a sufficient supply of reliable, steady workers. A rapidly expanding workforce is now estimated at more than 3 million workers, with home health aides and personal care aides projected to be the two fastest-growing occupations in the U.S.<sup>28</sup> The availability of workers varies geographically and may be especially problematic in rural areas. The impact of these variations on access, quality, and costs has not been examined.

Improving the quality of LTSS jobs would likely reduce worker shortages and turnover rates. Proposed improvements include better wages and benefits, establishment of career ladders, unionization, and other job enhancements, which could also result in improved quality of care for consumers. Suggested research in this area includes using state and area labor force variations to examine the impact of such practices on workers and consumers. Furthermore, the expansion of health coverage offered by the ACA is expected to have a major impact on this workforce, many of whom are not currently offered health insurance as a job benefit. The effect of this change on the HCBS workforce should be examined.

A key issue facing states and the federal government in attempting to improve LTSS quality is how (and whether) to organize, standardize, and improve worker training requirements. In the absence of federal regulations, some states have instituted limited standards, which can vary

widely across programs within and across states.<sup>28</sup> Outcomes of mandated versus voluntary worker training, and consumer direction of the training, have not been examined. Little is known about the efficacy of online and modular curricula and train-the-trainer approaches, in which paid workers would teach skills to family caregivers. Research is needed that explores the associations between amounts and types of training and workforce outcomes, such as retention and job satisfaction, as well as consumer satisfaction and quality measures.

As family caregivers age, they are at increasing risk of needing support themselves and are less likely to be able to provide unpaid care.<sup>29</sup> Basic research on the future need for and supply of family members providing personal assistance should be conducted, especially given changing demographics that will likely result in more elderly needing help and fewer younger people to help them.

A related issue is that of paying family members to provide LTSS, which is allowed under Medicaid programs in many states and can greatly expand the availability of paid workers, as well as giving consumers more choice in service provision. There are possible negative aspects of this development, which might merit further research. When regulations allow a consumer's family members to be paid to provide help, the economics of the situation are different from the traditional relationship between employer and employee, in which supply and demand play a role. Paid family members often provide more help than they are paid for, for example. For another, a dissatisfied consumer might not be able to fire his or her paid family member.

Finally, given all the attention to workers paid via public programs, the private-pay workforce is an under-researched topic. This large segment of LTSS workers is difficult to research, even to the extent that its exact size is not known.<sup>28</sup> More information is needed on who these workers are and how successful they are in obtaining private-pay work. Many workers in this category are immigrants, and it is possible that a large fraction of those might be undocumented. An interesting question is how immigration status affects the job, the quality of services provided, and the risk of the worker being exploited.

### Overarching themes

Based on the conference discussions, the authors identified the following as the most pressing LTSS research needs:

- (1) Research on the transition from fee-for-service to managed LTSS, in particular the shift of dual-eligibles into an integrated acute care and LTSS system.
- (2) Identifying LTSS outcome measures that focus on quality of services and the consumer's experiences, quality of life, community integration, and social participation.

- (3) More and better data collection and availability on LTSS need, unmet need, programs and services, and workforce.
- (4) Research on how to maintain and promote consumer-focused, consumer-directed services in the face of rapid changes to the LTSS system.
- (5) Research on equity or disparities by disability type, age, gender, race, and ethnicity in LTSS utilization, unmet needs, and family caregiver responsibilities and needs.

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## Appendix

Participating in State-of-the-Science Conference of the Center for Personal Assistance Services were Susan Allen (Brown University), Phillip Beatty (National Institute on Disability and Rehabilitation Research), Randall Brown (Mathematica Policy Research), Brian Burwell (Truven Health Analytics), Joe Caldwell (National Council on Aging), Letha Chadiha (University of Michigan), Henry Claypool (Administration for Community Living), Peggye Dilworth–Anderson (University of North Carolina, Chapel Hill), Pam Doty (Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services), David C. Grabowski (Harvard Medical School), Amy Houtrow (University of Pittsburgh Medical

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