

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).¹ 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 65.¹ 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.¹ 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.¹

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,^{2–5} with a few indicating a continued downward trend after 2000.^{6,7} Among the non-elderly, in contrast, the rate of need for LTSS appears to have been increasing.⁸ More recently, however, rates of the need for LTSS among both elderly and non-elderly adults appear to have leveled off.^{9–11} 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).¹² 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.¹³ 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 1960,¹⁴ 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 LTSS¹⁵ 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.¹⁶ 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 state¹⁷ and over time,¹⁸ 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,¹⁹ 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

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