Forum

Toward a Model Long-Term Services and Supports System: State Policy Elements

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In response to a new Federal initiative to improve the U.S. long-term services and supports (LTSS) system, this commentary discusses an array of policies and practices that could potentially improve LTSS provision by shifting from institutional to community-based services, increasing equity across populations, offering consumers more choice and control, improving conditions for workers and caregivers, and promoting improved consumer-level outcomes. Policy areas include access to publicly funded LTSS, support for consumer direction, workforce development, caregiver support, transition from institutions to the community, diversion from institutional placement, and quality and outcome measurement. Policy considerations apply both to programs and to the managed care organizations that are increasingly responsible for LTSS provision. Additional policy areas related to managed LTSS include financial risk and capitation rates, enrollment strategies, assessment, outcomes monitoring, care coordination, and support for independent living goals.

Key Words: Home- and community-based services, Consumer-directed services, Access to care

A model system of long-term services and supports (LTSS) could be characterized as one that promotes community living over institutionalization, integration over segregation, and full social participation over isolation (Commission on Long-Term Care, 2013; Harkin, 2013). Such a system should be equitable across age groups, disability categories, and other individual characteristics, economically sustainable yet generous enough to reasonably meet demand, and targeted broadly to include all people at risk of institutionalization, isolation, or functional decline in the absence of services (AARP, 2013). It should promote independence and autonomy, offering people the desired level of control over their services, and support in handling that responsibility (AARP, 2013; NCD, 2005). Family caregivers should be supported, and workers providing paid services should be given decent jobs and offered training to provide stable, reliable, respectful, and high-quality services (Commission on Long-Term Care, 2013; NCD, 2005). Finally, the entire LTSS system should be accountable through measurement and reporting of quality and outcomes, including indicators of expenditures, utilization, health status, and consumer quality of life, participation, and satisfaction (AARP, 2013; DREDF & NSCLC, 2013).

In the United States, publicly funded LTSS are provided largely through Medicaid, a state-administered program partially funded with Federal dollars. LTSS eligibility, services, and policies vary enormously from state to state, especially with respect to home- and community-based services (HCBS), which are offered as optional components of each state's Medicaid program (Harkin, 2013; Ng, Stone, & Harrington, in press). Some states narrowly restrict eligibility for HCBS or greatly limit program capacity or benefit levels, forcing people into institutions when they lack sufficient unpaid help or the means to pay for services out of pocket. Furthermore, states generally offer HCBS through multiple, narrowly targeted programs, leading to a fragmented and sometimes impenetrable system that may provide generous services to some, while only offering meager or no services to others with the same level of need. Consumers receiving HCBS generally have little choice of or control over their services, their families rarely get needed supports, and their workers generally receive poor wages and little or no training.

In 2013, the U.S. Department of Health and Human Services (HHS) established a Community Living Council to develop and implement a department-wide strategy to promote community living for people needing LTSS. HHS intends to "strengthen and further develop a high-performing LTSS system" that includes an emphasis on HCBS provided in integrated settings and offering such features as participant direction, consumer choice, care coordination and integration, and person-centered services (Community Living Council, 2014). The Centers for Medicare and Medicaid Services (CMS), the Administration for Community Living (ACL), and other HHS agencies will likely use funding opportunities and perhaps regulations to encourage states to improve their LTSS systems to incorporate policy elements that further the Community Living Council's vision. In connection with this effort, ACL joined with the National Institute on Disability and Rehabilitation Research to fund a Community Living Policy Center at the University of California San Francisco, in part to identify and study promising practices that have been implemented in one or more state or Federal LTSS system and might, taken together, constitute a model state LTSS system.

This article presents an overview of LTSS policy issues relevant to these efforts. Policies and practices can be divided into two categories: those that apply program- or statewide and those that apply specifically to integrated LTSS and acute health care programs operated through managed care organizations (MCOs). The scope is limited to policy areas over which HHS has potential influence, and excludes broader issues of funding amounts and sources, and the creation of a single nationwide LTSS pubic program or insurance system. Complex, ancillary topics such as expansion of affordable, accessible housing, transportation access, and improved livability of communities have been omitted because of space limitations but also need to be addressed by public policy.

Key Components of an Overall State LTSS System

Access to public LTSS programs varies across states and across disability and age groups, resulting in inequities based on where one lives, whether one's disability is lifelong or acquired, and which functions it affects. A complex, fragmented system is at the root of the problem, along with the "institutional bias" in Medicaid that treats HCBS as an optional service while institutional LTSS are mandatory.

- *Programs offered.* Most HCBS programs are offered at the discretion of the states, with eligibility criteria and the menu of services often varying by type of disability and age group. The 288 HCBS waiver programs operating under Section 1915(c) of the Social Security Act generally target a specific disability or age group; a cross-disability HCBS alternative is offered in 32 states that have chosen to create a personal care services program (Ng et al., in press).
- *Income and asset eligibility limits.* Financial eligibility for HCBS programs varies by state and program. Some require a household income less than the Supplemental Security Income (SSI) level, which is about three quarters of the Federal poverty level, whereas many HCBS waiver programs allow incomes up to three times the SSI level (Ng et al., in press). Some states expand eligibility by subtracting health care expenditures from the household's income. In 38 states, working people who exceed the usual income limits are allowed to "buy in" to Medicaid with a subsidized premium (Kehn, 2013). Aside from income, limits on financial assets are as low as $2,000 for many people qualifying for Medicaid on the basis of disability. Advocacy groups have encouraged policy makers to expand LTSS

eligibility to a uniform 300% of SSI and to greatly increase the asset limit (Howes, 2010).

- *Single point of entry, options counseling.* To reduce confusion over available LTSS programs, Aging and Disability Resource Centers serve as single points of entry in many states, offering options counseling to consumers and professionals seeking assistance on their behalf. Other states have innovative counseling programs run through state agencies (Summer & Howard, 2011). The Balancing Incentive Program in the ACA requires states to adopt a single-point-of-entry (or "No Wrong Door") approach.

- *Consolidation of programs.* Alternatively, states can streamline their LTSS systems to make them easier to navigate. For example, Vermont's Choices for Care, a global waiver program under Section 1115 of the Social Security Act, consolidates all HCBS and institutional services under a single umbrella. The program is unique in offering the two types of services on a completely equal footing, depending only on level of need (Kaiser Commission, 2006). The shift of LTSS to a managed care system also offers the potential to consolidate programs within the health plan's purview. New HCBS options from the ACA can also help consolidate programs.

- *Global budgeting.* Separate budgetary allocations for institutional and HCBS programs can work as a disincentive to rebalancing the LTSS system. A practice used in several states to foster rebalancing is global budgeting for all LTSS programs, or, more broadly, flexible accounting so that savings in institutional expenditures can be seamlessly reallocated to HCBS programs (Hendrickson & Mildred, 2012).

- *Assessment of need.* Uniform assessment of level of need across programs and disability categories helps promote greater equity in service provision (AARP, 2013). Development of a standardized LTSS assessment is a requirement of the Balancing Incentive Program in the ACA, and promising assessment tools are in use in Washington and Wisconsin (NSCLC, 2012a), among other states.

- *Cost-containment measures.* Most state HCBS programs fail to fully meet the assessed needs of people who require a lot of help. In all but eight states, HCBS programs place limits either on the number of hours of help a person can receive or on the total amount that can be spent on the person's services. Another cause of unmet need is a waiting period between application and receipt of services. More than 400,000 people are on waiting lists for HCBS waiver programs nationally, with some states having very long lists (e.g., 125,000 in Texas), whereas others have no such lists (Ng et al., in press).

Availability of and support for consumer-directed services is another key issue. Many HCBS programs incorporate some level of consumer direction, such as consumer choice in the allocation of service budgets or in the hiring and firing of service providers. By 2010, 44 states allowed consumer direction within some or all of their Medicaid HCBS programs (Ng et al., in press). Support for consumer direction can include the following:

- *Services from independent providers.* Programs in 36 states allow consumer direction of services received from an independent (nonagency) provider (Ng et al., in press). In some state systems, most notably California, independent providers are the norm, while an agency model predominates elsewhere.

- *Matching service registries.* First created in California in the 1990s, publicly funded registries exist in 19 states to help consumers find workers meeting their requirements. Consumers can either perform their own database searches or call the operating agency and request matches (Seavey & Marquand, 2011a).

- *Fiscal intermediary* or *financial management services* to shield self-directing consumers from the paperwork and other burdens of being an employer. These services can be provided by a quasi-governmental agency, a private payroll or similar business, or an independent living center, home health agency, or other provider (Scherzer, Wong, & Newcomer, 2007).

- The *ability to employ family members*, who are often the consumer's preferred source of consumer-directed LTSS, is allowed by PCS programs in 20 states, but only 4 states allow a spouse or legal guardian to serve as a paid helper (Ng et al., in press). California's In-Home Supportive Services program is often seen as the model for such a system.

- The *availability of backup help* in case the scheduled worker does not arrive is a particular problem for consumers using independent providers, who may have nowhere to turn if the worker does not show up. A few small-scale programs serve as models of this type of service (see, e.g., Access Living, 2008).

- *Consumer training* in hiring, supervising, and firing workers, and, if necessary, keeping records, making payments, and so on. Such training might be provided by independent living centers, fiscal intermediary agencies, or the HCBS program.
- *Flexible budgets* with which to pay for services, along with support in using them. The Cash and Counseling Demonstrations pioneered this approach, with good results in terms of greater satisfaction and reduced unmet need (Carlson, Foster, Dale, & Brown, 2007). More recently, the Department of Veterans Affairs (VA) has begun offering Veteran-Directed HCBS, which closely follows the Cash and Counseling model and offers support in budget planning and management (Department of Veterans Affairs, 2012a).

Another important but often neglected aspect of state LTSS systems is *workforce development* to promote a stable and sizeable workforce of appropriately skilled workers. Such activities could include the following:

- *Worker training* or *certification requirements*. In the absence of Federal standards for training or certification, half of the states impose a training requirement specifying a set number of hours (with a median of 40 hr minimum training), and one quarter of states had either a state-sponsored curriculum or a requirement for certification (Marquand, 2013). Although three fifths of consumers wanted their workers to be better trained (Consumer Voice, 2012), training requirements remain controversial, with some consumers preferring train their own workers rather than following instructions given by professionals. Furthermore, some advocates fear that required training would limit the pool of potential workers, especially by discouraging family members from seeking payment. Training could also be offered on a voluntary basis or at the discretion of the consumer.
- *Wages and benefits.* Personal assistance workers generally earn low wages that have not kept pace with inflations (PHI, 2012b), leading to high turnover, an inexperienced workforce, and, in some places, worker shortages. Wage increases in some programs have reduced turnover and markedly increased the availability of workers (Howes, 2005; Seavey & Marquand, 2011b). Working conditions could also be improved through offering health coverage as an

employment benefit, which many workers do not have. New Federal regulations will soon require employers to pay overtime to many workers for the first time, which will likely improve job conditions, but perhaps at the expense of cutbacks in the amount of help received by consumers.
- *Professionalization of the workforce.* Other efforts to improve recruitment and retention of personal assistance workers include developing career ladders, so that entry level workers could see a path to skill building and advancement to a more secure, more respected, and better-paid job (PHI, 2012a). However, professionalization, like credentialing, runs the risk of reducing the level of consumer direction and control and thus is not necessarily favored by disability advocates.

With caregiver stress identified as an important predictor of nursing home placement (Spillman & Long, 2009), *support for family caregivers* is crucial to the ability of many LTSS recipients to remain in the community over the long term. Caregiver support can take many forms:

- The Department of Veterans Affairs (2012b) offers perhaps the most comprehensive package of supports, available to the primary family caregiver of qualifying post-9/11 veterans. The package includes a monthly *stipend* in lieu of payment, reimbursement of care-related travel expenses, health coverage, *mental health services*, *training*, and *respite care*.
- Helping family caregivers prepare for, give input into, and handle *transitions* out of hospitals and institutions and back into the community is the focus of another innovative practice (Levine, Halper, Rutberg, & Gould, 2013).
- The ability of paid LTSS workers to perform certain *health care-related tasks* is advocated as an important support for family caregivers, who would otherwise have to perform those tasks themselves. Sixteen states allow tasks such as administering oral medications and injections, ventilator care, and tube feeding to be performed by attendants or aides rather than nurses (Reinhard, Kassner, Houser, & Mollica, 2011).
- Increased access to *assistive technology* and *home modifications* through public programs is proposed as a strategy to reduce physical strain and overall burden among family caregivers, as well to help consumers maintain community living (The Lewin Group, 2012). *Remote monitoring*, often proposed to ease caregiver stress,

is being piloted and evaluated by senior care organizations in several states (Magan, 2011).

Efforts to *transition institutional residents back to the community* have gained prominence with the Money Follows the Person (MFP) Demonstration, which was extended until 2016 in the ACA. MFP focuses on long-stay residents who are Medicaid beneficiaries, offering services such as care coordination, personal assistance, and technology for up to 1 year following return to the community. Although some state MFP programs have transitioned large numbers of residents, the overall transition rate is very low (Irvin et al., 2012), reflecting the difficulty in returning to the community people who may have given up their housing and support systems, and even lost independent living skills. Innovative approaches to transition include the following:

- *Early intervention* strategies offer transitional supports to nursing home residents early in their stay. The Minnesota Return to Community program targets residents staying 60–90 days and provides care coordination following discharge, resulting in substantially increased transition rates (Arling, Dennis, Kane, Woodhouse, & Abrahamson, 2012).
- Some states offer *transitional assistance services* or *community transition services* through Medicaid HCBS programs, potentially making them available to a broader population and over a longer period than MFP. Several states, including Texas, Massachusetts, and New York, require health plans to offer transitional services as part of a managed LTSS system.
- *Peer mentoring* and *peer support programs* have been successful in facilitating transition of long-stay institutional residents. Mentors can serve as role models for consumers dubious of their ability to thrive in the community (San Francisco IHSS Public Authority, 2013), and peer support programs are being implemented to promote community transitions of people with mental health disabilities (Sudders, 2013).

Diversion from institutional placement for people at high risk is the focus of innovative practices in several states, where rapid eligibility decisions hasten access to HCBS and avoid unnecessary institutionalization. Several states use posthospital assessment procedures that can be conducted within a few days, and Washington has a provisional eligibility system that authorizes HCBS waiver services while the application is being completed (Summer & Howard, 2011).

Assessments of state LTSS systems often focus on expenditures on institutional services versus HCBS, numbers of participants in different programs, amounts of services received, and policies that have been put into place. Although these characterizations are important, they are no substitute for *measuring quality and outcomes*, such as adequacy and appropriateness of care and the consumers' level of integration, control, participation, and general quality of life. Several national, state, and university efforts are being undertaken to develop measures covering one or more of those areas (for a summary, see DREDF & NSCLC, 2013):

- The Measure Applications Partnership (2012), convened by the National Quality Forum, proposes LTSS and health care quality measures including consumer choice, life satisfaction, and community participation.
- The Agency for Healthcare Research and Quality (2010) identified measures of Medicaid HCBS quality, including consumer choice, control, and satisfaction.
- The Centers for Medicare and Medicaid Services (2012) funded the development of several "personal experience surveys" for use by HCBS programs. The latest, developed by Truven and AIR and released in 2012, contains measures of met and unmet need for LTSS, choice of and satisfaction with services, and community participation.
- Wisconsin's Personal Experience Outcomes Integrated Interview and Evaluation System (PEONIES) identifies domains of a conceptual framework for HCBS outcomes, rather than actual measures (DREDF & NSCLC, 2013). Three domains relate to choice and making one's own decisions, three to social and community participation, three to appropriate treatment by paid workers and others, and the remaining three to health, safety, and stability.

Key Components of an Integrated, Managed LTSS Program

A decade ago, only a few states operated programs offering LTSS under a managed care model. Now there are 43 managed LTSS systems or demonstration projects active, or proposed and awaiting approval, in 30 states (NASUAD, 2013). In these, LTSS is offered as a component of an integrated, managed system that also includes acute

health care services. One goal is to provide better-coordinated and more effective services than does the traditional, highly fragmented, fee-for-service system. Another goal is to save money by eliminating duplication and better containing costs.

Eighteen of the 30 states have or plan to have so-called duals demonstration projects involving managed LTSS. These projects, for beneficiaries of both Medicare and Medicaid, are aimed at integrating the two programs into a single, nonduplicative package. Most states will use a *financing model* in which the MCO is given a capitated payment, or a set amount for each member to provide all needed health care and LTSS. In three of the programs, however, an alternative model known as managed fee-for-service is being used (Medicare-Medicaid Coordination Office, 2013). In this model, the state coordinates Medicare and Medicaid benefits to provide "seamless integration and access to all necessary services" and gets to share in any cost savings resulting from the integration (Mann & Bella, 2011).

Perhaps the most important difference between the two models is that, in a capitated model, the MCO assumes *financial risk* for all expenditures, providing a strong motivation to reduce costs. In the managed fee-for-service model, providers are not at risk, but the state has a financial incentive to reduce costs. Whether these approaches result in better care coordination or cutting corners in service provision, or both, is a key question for evaluation. An appropriately structured capitated model, including LTSS across all settings, could provide an incentive for MCOs to favor HCBS over more costly institutional services, thus hastening rebalancing of the LTSS system, and to work to transition nursing home residents back into the community (NCD, 2013). In contrast, programs that carve out institutional services might offer the plans an incentive to unnecessarily send people into nursing homes (Dembner, 2012).

Apart from the duals demonstrations, 21 states operate managed LTSS programs for Medicaid-only participants (NASUAD, 2013). Among both the duals demos and the other Medicaid managed LTSS projects, there is tremendous variation in program characteristics and populations served. A few programs have statewide scope and serve people of all ages with all types of disabilities, but most are more limited: operating only in selected regions of the state, or offered only to specific age groups, or targeted to or excluding people with a particular type of disability. The diversity of programs makes

for an interesting test bed of practices that might prove effective in both service provision and cost containment.

One key distinction among the programs is whether *enrollment is mandatory or voluntary*, and, if the latter, whether consumers must opt in or are "passively enrolled" with the opportunity to opt out. Advocates prefer an opt-in approach (NSCLC, 2012b), which has been successfully used by large programs in Wisconsin and Minnesota (Dembner, 2012). For their part, states probably prefer transitioning everyone to avoid having to maintain two parallel systems. Different enrollment processes also affect the ability of researchers to compare managed care models with fee-for-service or to make comparisons across types of models, due to possible self-selection bias.

Assessment of level of need is of particular concern in a managed LTSS framework. Fearing that health plans would underassess people's needs, advocates have promoted third-party assessment that is free of conflicts of interest (AARP, 2013; Dembner, 2012). Third-party assessments, performed by government agencies or community-based organizations, are part of the duals demonstration projects in several states.

Quality and outcome measurement is even more important in managed LTSS than in fee-for-service systems. In a managed care environment, there is a risk that MCOs will become a black box, providing services but not reporting even basic measures of expenditures and populations by setting. Closely related is the issue of who is keeping track of and reacting to these indicators. When states transfer service provision to private entities, a state agency must be empowered and staffed to *monitor and enforce contractual agreements* and ensure quality and adequacy of service provision. Advocates encourage states to have an oversight and monitoring plan to track and resolve problems with MCO performance (NSCLC & DREDF, 2012).

Furthermore, *ombudsman programs*, whether run by a state agency or an independent, quasi-official body, can protect the interests of consumers in dealing with MCOs. Advocacy organizations serving in such roles could prove a promising strategy for protecting consumer rights. Disability Rights Wisconsin operates the ombuds program for younger adults getting LTSS in that state (Dembner, 2012).

Several issues in managed LTSS must be assessed at the MCO level, rather than program-wide. Some of these are similar to those discussed

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with reference to the entire state LTSS system, such as *support for consumer-directed services*, *work-force development*, *support for family caregivers*, and programs for *transition* out of institutions and *diversion* from institutional placement. *Coverage issues*, such as consumers' ability to obtain durable medical equipment and other assistive technology, are also key.

Care coordination is another important issue because the ability to coordinate services is one of the purported benefits of the managed, integrated care model. Advocates promote multidisciplinary care coordination including people knowledgeable about available community supports (AARP, 2013) and with expertise in LTSS rather than solely clinical matters (NSCLC & DREDF, 2012). As with assessment, coordination of services might be optimally provided by a third party, free of conflicts of interest that could provide a financial incentive to cut services (NCD, 2013).

A related issue is the extent to which the MCOs, health care organizations used to treating illness, gain a better understanding of the importance of LTSS in *fostering independent living and community participation*. Aside from meeting basic needs, LTSS enables many consumers to leave their homes, work, and engage in community activities. States could require plans to incorporate employment and other community participation supports into their benefits (BCIL, NCIL, Community Catalyst, DREDF, & Tri-County Independent Living Center, 2012). Offering MCO staff and providers training in these issues might be beneficial. Training may also be needed in *cultural competency* to handle the influx of new members with disabilities and their accommodation needs.

Conclusions

In furthering its goal of strengthening the U.S. LTSS system, HHS should encourage and support states in broadening HCBS offerings to better meet consumers' needs, consolidating fragmented programs and standardizing eligibility to increase equity across populations, and assisting consumers in enrolling in appropriate LTSS programs and in giving them greater choice and control over their services, including the ability to return to the community from an institutional setting if they want to. Federal and state policies should promote a stable and appropriately skilled LTSS workforce by improving job quality and should find ways to support family caregivers in continuing to provide the

help that consumers need. HHS should require, and states should welcome, expanded efforts to measure LTSS quality and outcomes, relying not only on administrative data but also on direct feedback from consumers. Although numerous existing programs and demonstration projects suggest potential strategies to achieve these purposes, further research is needed to identify and confirm promising practices in many of these policy domains.

Several policy issues, such as quality and outcome measurement, are of particular concern as states continue the rapid process of transitioning LTSS consumers into integrated, managed care programs. State agencies be empowered to monitor quality and enforce requirements for high-quality services. The needs of consumers must be protected by their getting assessed for services fairly by entities without a conflict of interest, getting support in resolving problems encountered in dealing with the MCOs, and being given the option of remaining in or returning to a fee-for-service system if needed. HHS and the states need to be especially vigilant in ensuring that MCOs retain and enhance the ability for consumers to direct their own services and continue to receive services that are not strictly health care related but are more generally aimed at supporting people in participating fully in their communities.

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