Advancing Home and Community-Based Services: Transforming Policies, Programs, and Service Delivery in Long-Term Care
More Change than Continuity?
The Evolution of Long-Term Care Policy

Robert B. Hudson, Editor

After years of only modest movement, the ground under long-term care policy is shifting to a very significant degree. Eligibility is expanding, benefits are becoming more flexible and innovative, the delivery system is undergoing a paradigmatic shift in the direction of consumer choice, and new financing mechanisms are gaining a foothold in the system.

This issue of Public Policy & Aging Report brings both attention and perspective to these notable changes. Pamela Doty’s introductory essay provides a 30-year review of the evolutionary process, where movement has gone from glacial to visible. Of the themes she touches on, the rise of insurance mechanisms is of particular interest. Private long-term care insurance is carving out a market for itself, and it is now to be joined by the remarkable CLASS Act passed in February as part of health care reform. Making long-term care a social insurance as well as a public assistance benefit represents a policy change of truly momentous proportions. Coupled with private (and public/private) insurance options, enactment of the CLASS Act means that there is coming into place a wide (if not deep) range of insurance options available for those in need of long-term care services.

As outlined by Lori Simon-Rusinowitz and colleagues, consumer-directed initiatives represent a truly innovative development in service delivery. Maturation of the service delivery system is also seen in the new capacities of aging network agencies to manage community-based services as demand and financing for them increases, as noted by Suzanne Kunkel and Abbe Lackmeyer. Workforce issues, of course, continue to be a major concern in the field, and the work of the national panel reported here by Benjamin Rose Institute researchers sets forth concrete if difficult steps that can be taken. That family caregivers may over time join the formal as well as the informal long-term care workforce represents a major possibility, albeit a controversial one.

Whether or not developments along so many fronts can be controlled and coordinated will continue to be a major question. Miriam Rose and colleagues review recent state-level initiatives in home and community care. For example, Ohio represents one testing ground for finding answers to this question, and the state’s long-term care system is put under the microscope here by researchers at Miami University of Ohio. We believe that this issue of PP&AR serves as an excellent “one-stop shop” for seeing where long-term care has evolved and how it may be positioned for the future.

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The Evolving Balance of Formal and Informal, Institutional and Non-Institutional Long-Term Care for Older Americans: A Thirty-Year Perspective

Pamela Doty

Shifting the center of gravity in the long-term care financing and service delivery system away from institutional care toward home and community-based services (HCBS) has, in one way or another, been a federal policy goal since the late 1970s. Long Term Care: Background and Future Directions, a report published in January, 1981, by the Office of Policy Analysis in the Health Care Financing Administration (now known as the Centers for Medicare and Medicaid Services), identified “limited access to services” attributed to public program “bias toward institutional and skilled medical care” as among the major problems of the U.S. long-term care system (United States Health Care Financing Administration, Office of Policy Analysis, p. 25). The report also stated that “a consistent theme in policy deliberations on long-term care reform is the desirability of expanding in-home and community-based services” (p. 31). Over the past three decades, federal and state policymakers understandably have focused most of their attention and reform efforts on publicly-financed long-term care. In recent years especially, policymakers have defined the goal primarily in terms of “balancing” (or “re-balancing”) state long-term care financing and service delivery systems with respect to promoting greater reliance on HCBS rather than institutional care.

As the articles in this issue by Rose and colleagues and Kunkel and Lackmeyer explain, there are multiple federal and state funding streams for HCBS, and the aging network has assumed an increasingly important role in coordinating financing and services and in providing information and referral, including to private payers. The article by Noelker and colleagues highlights the role of the aging network in growing the long-term care workforce and addressing the services and support needs of family caregivers. In their two articles, Simon-Rusinowitz and colleagues point out that Medicaid- and Older Americans Act-funded programs have pioneered new approaches to service delivery. They cite, in particular, evidence-based models of consumer-directed services such as Cash and Counseling. These programs offer service users and their families greater choice and control over HCBS and support family members’ long-term, intensive commitment to eldercare by allowing them to receive payment for at least some of help they provide. Applebaum and colleagues describe how the aging network in Ohio has been able to tailor a range of interventions specific to regional areas within the state to promote higher rates of nursing home diversion and transition. The recent state budget crisis threatened and postponed but has not stopped reform efforts that both the Governor and the legislature had agreed were necessary to give greater momentum to the re-balancing of Ohio’s long-term care system in favor of HCBS.

Nevertheless, while celebrating these improvements in public funding, administration, and infrastructure development for HCBS, it is important to understand the limitations of existing public programs. At any given point in time, a majority of older Americans with chronic functional disabilities do not meet coverage and/or financial eligibility for publicly funded long-term care, or cannot access services they do qualify for because of workforce, provider agency, or public funding shortages. State long-term care systems are predominantly dependent on Medicaid funding and the Medicaid means test is very stringent. As a result, many older Americans with chronic disabilities are not eligible for Medicaid-funded HCBS; they only can gain Medicaid coverage by entering a nursing home and “spending-down” their assets until they qualify. Older Americans Act funding for HCBS can be targeted to help such elders avoid nursing home admissions, but is very limited. To put the role of Medicaid and other public programs in perspective, this overview will describe how patterns of long-term care service use and financing have and have not changed over the past three decades for those aged 65 and older.

Patterns of Reliance on Residential Eldercare (Nursing Homes and Other Facilities)

In the last 30 years, there has been a marked decline in the age-adjusted percentage of older Americans residing in nursing homes. The 1977 National Nursing Home Survey (NNHS) identified...
1.1 million nursing home residents aged 65 and older (approximately five percent of older Americans). Projecting the 1977 NNHS age-adjusted rates of nursing home use forward, CMS officials anticipated in 1980 that growth in the elderly population would result in 1.7 million nursing home residents aged 65 and older by 2000. Instead, the 2004 NNHS found only 1.3 million elderly nursing home residents (Jones, Dwyer, Bercovitz, & Strahan, 2009). Since 1977, the age-adjusted rate of nursing home use initially increased, then began to decline from 1985 onward. Most of the decline in older Americans’ use of nursing homes has occurred since 1995—indeed, since 1999—and has been greatest among elders age 85 and older (Federal Interagency Forum on Aging Related Statistics, 2008).

Based on a representative sample of Medicare beneficiaries age 65 and older, the National Long-Term Care Survey (NLTCS) was fielded in 1982, 1984, 1989, 1994, 1999, and 2004. Although it includes some non-disabled elders for purposes of comparison, its focus was primarily on older Americans in need of long-term care because of functional disabilities. Over most of its history, the NLTCS found that about one in four chronically disabled elders resided in facilities characterized as long-term care “institutions” (including but not limited to facilities licensed or certified as “nursing homes”). As of 2004, however, only one in five chronically disabled NLTCS respondents resided in residential eldercare settings of this type; seventy-two percent lived in private homes and 7.5 percent lived in “non-institutional” community-based residential settings.

What factors explain the decline in older Americans’ nursing home use? It was clear from several different surveys of older Americans conducted between 1999 and 2002 that one-third of all functionally dependent elders living in residential eldercare settings were in places other than in nursing homes (Spillman & Black, 2006). It is noteworthy that, whereas disabled elders’ use of nursing home care has decreased, their overall use of specialized residential eldercare settings—including both “institutional” and “community-based”—appears to have increased (6.5 percent of older Americans lived in specialized residential eldercare settings). Many chronically disabled elders living in residential eldercare settings that are not federally certified or state-licensed as nursing homes have comparatively low levels of disability. Indeed, those in residential eldercare settings other than nursing homes are often less disabled than other chronically disabled elders who remain in private housing. In comparison to disabled elders living in private housing, those in residential eldercare settings other than nursing homes tend to be older, are more likely to be single or widowed, have somewhat lower incomes, and are more likely to have at least mild cognitive impairment. This suggests that for a certain group of frail elders, specialized residential eldercare settings other than nursing homes are an attractive alternative to “home care” as well as nursing homes.

For the most part, assisted living serves predominantly private payers when it is broadly defined, and especially in so-called “high end” facilities offering high privacy and a broader range of personal assistance service, including nursing. Although only 10 percent of Americans age 65 and older have long-term care insurance coverage (15 percent of those with annual incomes over $20,000), if such coverage were to become more prevalent, it almost certainly would further decrease private payers’ long-stay nursing home use in favor of increased use of assisted living and paid home care. Recent findings from a longitudinal study of an admission cohort of private long-term care insurance claimants found that only one in five ever used nursing home care. Although most claimants at any given point during the 28-month study period were living at home, among paid service users a slightly higher percentage of claimants were in assisted living rather than receiving paid home care (Doty, Cohen, Miller, & Shi, 2010).

Both government and industry sources estimate that only about 10 to 15 percent of assisted living residents have Medicaid as a payer source. The low prevalence of Medicaid beneficiaries reflects two factors: the statutory prohibition on Medicaid reimbursement for “room and board” costs except for institutional long-term care; and, the inability of individuals who are financially eligible for Medicaid to cover those costs from public assistance or pension income.

Nevertheless, the growth of assisted living almost certainly has reduced use of Medicaid-financed nursing home care. For a variety of reasons, private pay assisted living residents rarely transition to nursing homes because they have “spent-down” and Medicaid will not cover their full costs in assisted living. When assisted living residents do move on to nursing homes it is typically because their physical and/or cognitive disabilities have reached a high level of severity, they are at end-of-life, and therefore their nursing home stays
tend not to be lengthy.

The nature of nursing home care also has changed greatly over the past 30 years in ways that both have spurred the growth of residential eldercare alternatives and have responded to the growth of assisted living. In the late 1970s and early 1980s, there were two categories of certified nursing facilities: “skilled” (SNFs), which could serve Medicare post-acute patients, and “intermediate care” (ICFs), which only could serve Medicaid consumers in need of what was then termed “custodial care.” In 1972, Medicaid had expanded coverage to include ICFs that previously had only been state-licensed to provide “board and care” and could be publicly financed only via income assistance (SSI/SSP) or with social services funds. Medicaid provider qualifications allowed ICFs to be staffed exclusively with nurses’ aides and licensed practical nurses in contrast to SNFs, which were required to have a registered nurse as charge nurse on the day shift seven days a week. In the late 1980s, Congress passed nursing home quality improvement legislation requiring all facilities eligible for Medicare or Medicaid reimbursement to meet the higher “SNF” staffing requirements. This meant that “ICFs” had three choices: they could staff up and make other changes to remain Medicaid-qualified providers; they could close and revert to being “board and care” facilities primarily catering to low-income elders eligible for SSI/SSP with low levels of disability; or, their owner/operators could choose to renovate or replace them to attract private payers under the emerging category of “assisted living.”

Concomitantly, nursing homes became even more oriented toward providing medical and nursing services and served increasingly more severely disabled residents whose average lengths of stay decreased. In 1979, Medicare paid for only two percent of calendar year nursing home expenditures. The growth in use of Medicare SNF benefits in nursing homes began in 1982 when Medicare introduced the Diagnostic Related Groups (DRG) prospective payment system for hospital stays. This gave hospitals a powerful financial incentive to shorten Medicare-covered hospital stays, discharge elderly patients as soon as possible, and make greater use of Medicare’s post-acute (home health and SNF) benefits for this purpose. Nevertheless, it took many years for the percentage of Medicare-covered SNF stays in NFs to reach the present level: 13 percent of nursing home residents on any given day, according to the 2004 NNHS, and 32 percent of annual nursing home expenditures in 2009, up from 23 percent in 1999 (Ng, Harrington, & Kitchener, 2010).

The NLTCS and other surveys also evidenced the declines in disability rates among older Americans that, to some extent, may also help explain older Americans’ declining reliance on nursing home care, although this is difficult to measure directly. In the NLTCS, disability declines were observed over the period from 1982 to 1999 (Spillman, 2003), but this mainly involved dependency with respect to “instrumental activities of daily living” (IADLs), that is, activities such as house cleaning, grocery shopping, and meal preparation, but also including medication management, money management, and getting around outside the home. These are distinct from the basic “activities of daily living” (ADLs) that measure dependency on assistance with basic personal care tasks such as bathing, dressing, transferring, toileting, and eating.

“Disability” is a social construct insofar as it reflects the ease or difficulty that individuals with physical impairments experience interacting with the built and social environments. Most long-term care experts are not convinced that disability declines observed among older Americans during the 1980s and 1990s reflect advances in medical science, increased access to medical care, or real improvements in health status. More likely, declines in IADL disability result from disability-friendly environmental changes. The plausibility of this hypothesis is strengthened by the persistent trend in the NLTCS (through 2004) of increased reliance on assistive technologies, including a growing percentage of chronically disabled elders who rely exclusively on assistive devices (Spillman & Doty, 2009). This line of reasoning makes sense if we consider the environmental modifications brought about as a result of disability rights advocacy over the past thirty years: curb cuts, handicapped access ramps and elevators, handicapped parking and transportation services, hand controls for driving and van lifts, grocery shopping carts designed for disabled users, to name some of the most visible environmental accommodations for people with disabilities. There also have been improvements in assistive devices for people with mobility impairments (wheelchairs, scooters) that are better designed and/or electrically powered. As a result, many elders as well as younger persons with mobility impairments are able to get around better outside the home without the help of another person. It also has been suggested
that simply the introduction of direct deposit of Social Security checks and other banking conveniences may have reduced disabled elders’ dependency on others for assistance with money management. A more controversial hypothesis, but one that merits further research, is that higher levels of educational attainment among older Americans have resulted in lower levels of cognitive impairment, especially insofar as cognitive impairment first presents as dependency on others for help with IADLs.

One factor that counter-intuitively does not appear to be related to changes in older Americans’ use of nursing home care is Medicare’s coverage of and reimbursement for home health services and associated patterns of service use. During the 1980s, even after the introduction of Medicare’s prospective payment reimbursement system for hospitals, CMS maintained restrictive coverage policies for Medicare home health services that tightly controlled growth in the use of these services. In 1989, however, there was a surge in use and cost of Medicare home health services following a class action suit and related loosening of coverage restrictions for Medicare home health services. After 1989, the use and cost of Medicare-funded home health services took off, namely lengthy episodes of home health services use involving large numbers of home health aide visits. This caused concerns in Congress about the impact of growing expenditures for Medicare home health services on the solvency of the Medicare Part A trust fund. Through the better part of the 1990s, use of Medicare home health services soared, particularly among chronically disabled elders who had lengthy episodes in which home health aide services greatly outnumbered skilled nursing and rehabilitation visits. This caused concerns in Congress about the impact of growing expenditures for Medicare home health services on the solvency of the Medicare Part A trust fund. Through the better part of the 1990s, use of Medicare home health services soared, particularly among chronically disabled elders who had lengthy episodes in which home health aide services greatly outnumbered skilled nursing and rehabilitation visits. This caused concerns in Congress about the impact of growing expenditures for Medicare home health services on the solvency of the Medicare Part A trust fund. Through the better part of the 1990s, use of Medicare home health services soared, particularly among chronically disabled elders who had lengthy episodes in which home health aide services greatly outnumbered skilled nursing and rehabilitation visits.

In the Balanced Budget Act of 1997, Congress mandated prospective payment for Medicare home health services. This occurred first through the interim prospective payment system that went into effect in 1999. In subsequent versions of the final prospective payment system, increasingly stronger financial incentives were established for home health agencies to focus on providing skilled services to post-acute patients. These incentives also resulted in cutbacks on the provision of home health aide services as well as services provided—especially on a long-term basis—to Medicare beneficiaries without immediate prior hospital stays. The result was that beginning in 1999, chronically disabled elders living in the community became much less likely to receive Medicare-covered “long-term” home health services, especially long-term home health aide services. Logically, it might seem that nursing home use among chronically disabled elders living in the community should have decreased during the period between 1990 and 1998 when Medicare-covered home health services were widely available over long periods of time to those who had “nursing-home-level-of-care” needs (i.e., three or more ADL dependencies). And yet, nursing home use declined relatively little during this period. The precipitous decline in nursing home use dates from 1999, a point when the Medicare home health interim prospective payment system had begun already to restrict access to Medicare-funded aide services.

A key question, given the emphasis in Medicaid long-term care policy on “re-balancing,” is whether or not the extent to which growth in Medicaid funding for HCBS has contributed to the decline in nursing home use. A number of studies have come to conflicting conclusions. Assistant Secretary for Planning and Evaluation (ASPE)-sponsored analyses of Medicaid Analytic Extract (MAX) files confirm and amplify findings from other studies that the shift toward reliance on HCBS has been much greater with respect to services for Medicaid beneficiaries at younger compared to older ages. Community-based service expenditures as a share of total long-term care expenditures are: 50 percent for people under age 65, 31 percent for people between ages 65 and 74, 21 percent for people between ages 75 and 84, and 13 percent for those age 85 and older (Wenzlow, Schmitz, & Gurvey 2008). In states where higher percentages of nursing home residents (who are predominantly elderly) had previously received HCBS, however, nursing home lengths of stay were much shorter than in states where lower percentages of nursing home residents had received HCBS prior to their nursing home stays. This suggests that use of HCBS tends to postpone nursing home use even when it is not prevented (Wenzlow, Schmitz, & Shepperson, 2008).

Comparative Reliance on Informal and Formal HCBS

In 1999 and 2004, two thirds of chronically disabled NLTCS respondents relied exclusively on informal care—similar to patterns observed in 1984 and 1989. Access to paid home care briefly increased during the mid-1990s, according to the 1994 NLTCS.

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It is now clear that this was primarily a result of the expansion in Medicare home health services coverage of home health aide services. The subsequent decrease in use of paid care occurred primarily as a result of the cutbacks in Medicare-funded aide services attributable to the interim and final prospective payment reforms mandated under the 1997 Balanced Budget Act that went into effect in 1999.

In 2004, disabled elders living in the community relied less on human assistance (including informal help) than in earlier surveys because they relied more on assistive technologies and environmental modifications. Chronically disabled elders in the community who received human assistance, however, had on average higher levels of disability than in earlier years, and in particular, more of their primary informal caregivers provided assistance with personal care in 2004 than in 1999 (64 percent compared to 56 percent). Almost one in five caregivers reported high stress, a concern because high caregiver stress was found to predict subsequent long-stay nursing home admissions among 1999 NLTCS respondents living in the community and receiving informal help.

Clearly, changes in family composition (e.g., rates of childlessness, divorce) and female labor force participation have not reduced chronically disabled elders’ access to informal care over the last 30 years, as CMS officials had speculated in 1981. In 2004, only about 30 percent of primary caregivers were employed, which was not much different from 1994 or 1999, and indeed, only a few percentage points higher than in 1982. As in early rounds of the NLTS, few primary informal caregivers (6.5 percent in 2004) said that they had quit a job to provide care. Most who previously had worked had retired for reasons unrelated to eldercare (Spillman & Doty, 2009).

Sources of Payment for Formal Home Care
In 1980, only a handful of states had elected to include optional coverage of personal care services under their Medicaid state plans, and nationally, New York accounted for most of these expenditures. Funding for non-medical personal care, chores, respite, and adult day services was provided, where available, from: “social services” funding under Title XX for which the Reagan Administration capped federal funding and renamed the Social Services Block Grant, and state-revenue financed programs whose size and scope varied greatly across states.

In 1981, Congress enacted the 1915(c) home and community-based waiver program. Although both availability and funding for HCBS waiver programs and state plan personal care services grew during the 1980s, this growth did not result in an immediate sizable increase in the overall percentage of Medicaid long-term care expenditures going toward HCBS rather than to institutional care. One reason was that for the first dozen years, during the Reagan and Bush Administrations, states seeking HCBS waiver approval often were asked to document that nursing home or ICF/MR beds equal to the number of new waiver slots being requested would be closed. Alternatively, if beds had been approved for construction under “Certificate of Need” requirements, they would not be built. This requirement—known as the “cold bed” rule—was criticized widely for limiting the expansion of home and community-based services. However, during the Clinton Administration (1994), the National Governors’ Association reached an agreement with CMS that CMS no longer would take institutional bed supply into account in reviewing states’ waiver requests. Still, by 1999, HCBS accounted for only 20 percent of Medicaid long-term care expenditures for the elderly and younger adults with (non-developmental) disabilities. The Supreme Court’s 1999 Olmstead ruling, based on the 1990 Americans with Disabilities Act, directed states to strive to serve people with disabilities in the community as far as it was possible and practical to do so. As a result, federal initiatives to encourage compliance with the Court’s ruling spurred expansion of Medicaid funding for HCBS. Yet, this has had far greater impact on shifting the balance toward decreased use of institutions and greater reliance on HCBS for persons under age 65 with physical or intellectual disabilities than for chronically disabled elders.

In the 2004 NLTCS, among chronically disabled elders in the community who reported receiving any paid home care, 54 percent (up 4 percentage points from 1999) reported paying “out-of-pocket” for such assistance (16.5 percent of all NLTCS respondents who received human assistance). Medicare was the second most commonly cited payment source and was mentioned by 25 percent who used any paid care, and by 7.5 percent of all NLTCS respondents receiving any human assistance. The percent of formal home care users reporting Medicaid as a payer source was 17.5 percent of all respondents receiving paid home care (5.3 percent of all who received any human assistance).
Compared to previous NLTCS, Medicaid’s role as a payer source clearly had increased (up 8 percentage points among formal service users compared to 1994, and up 1.8 percentage points compared to 1999). The role of private insurance as a payer source for formal care remained small. It was cited by 8.7 percent of formal service users in 2004, which was up 4.8 percent points from 1999, but still only 2 percent of all NLTCS respondents receiving human help. It is noteworthy, however, that the percent of formal home care users who cited private long-term care insurance as a payer source in 2004 was about the same as the percent of formal services users who cited Medicaid as a payer source in 1994 (Spillman & Doty, 2009).

### Summary and Conclusions

Measured from one year to the next or even over several years, changes in the balance of reliance on formal and informal long-term care, relative dependence on human assistance and assistive technologies, and use of institutional and other forms of residential eldercare compared to receipt of paid and unpaid care at home may appear to have occurred at a glacial pace. However, viewed from a 30-year perspective, cumulative changes have been quite substantial, although reliance on informal care remains very much the backbone of the U.S. system of long-term care for older Americans with chronic functional disabilities.

Over the years, there also have been gradual, sometimes subtle, but nonetheless meaningful changes in public policy goals with respect to promoting expansion of HCBS. In the late 1970s and into the 1980s, the emphasis was very much and very literally on HCBS “alternatives” to institutionalization. The goal was to have HCBS substitute for nursing home care in such a way that reductions in nursing home use would result in cost savings sufficient to pay for expanded funding of HCBS. This goal proved largely elusive. Only one controlled experimental design evaluation in recent years (the “Cash and Counseling” Demonstration and Evaluation in Arkansas) documented enough savings from reduced nursing home use over three years to offset high costs associated with increased access to personal assistance services among mostly elderly program participants (Dale & Brown, 2006). As a result, federal and state policymakers gradually and tacitly have come to accept that, whereas HCBS clearly costs less per person served than nursing home care would cost, in terms of aggregate public costs expanding funding for HCBS requires some growth in total spending on long-term care. Most federal and state policymakers agree that reducing nursing home use and costs is not the only worthwhile motive for financing increased access to HCBS. Improving quality of care, reducing unmet needs for assistance, improving quality of life and satisfaction with services, and mitigating family caregiver stress are all legitimate policy goals regardless of whether or how much nursing home use declines and Medicaid saves money as a result.

The availability of private long-term care insurance coverage, the spread of Medicaid/private long-term care insurance partnerships (now underway or about to get underway in almost all states in response to the 2005 Deficit Reduction Act’s elimination of previous legislative restrictions), and the very recent passage of the Community Living Assistance Services and Supports (CLASS) provisions as part of health reform seem likely to usher in a new era of changes to the U.S. long-term care financing and service delivery system. What public, private, and public/private long-term care insurance approaches all have in common is that policyholders become eligible for benefits based on meeting a threshold of disability severity, not based on whether or not they qualify for an institutional level of care and whether or not third-party payers would prefer them to receive less expensive services in other settings. All three of these insurance-based approaches to financing long-term care services provide elders in need of long-term care more choice and control over where and how they receive the assistance they require. Insofar as any given level of daily dollar benefits will go further toward covering the costs of home care or assisted living than nursing home care, all of these newer financing mechanisms seem likely to promote further expansion of reliance on paid HCBS and non-institutional forms of residential eldercare.

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References


Recent Findings on Home and Community-Based Services Across the States

Miriam Rose
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The “perfect storm” in long-term care appears to be on the horizon. The first Baby Boomers are retiring and life expectancy is increasing (U.S. Department of Health and Human Services, 2009). The prevalence of chronic disease among the near elderly is rising, foreshadowing increasing morbidity in the next cohort of older adults (Goldman et al., 2005). As a result, it is likely that there will be greater demands for long-term care and services, putting more pressure on overextended federal and state budgets, a growing percentage of which are consumed by burgeoning Medicare and Medicaid costs. It is an ideal environment for the aging network to plan for and execute the expansion of home and community-based services (HCBS), a less expensive alternative to long-term care in nursing homes and an approach that accommodates the preferences of most consumers to remain living independently as long as possible (Gibson et al., 2003). Expansion of HCBS is essential to the success of “rebalancing” efforts, guided by the values of choice, independence, and dignity that seek to shift the disproportionate share of Medicaid expenditures and the prevailing mindset from long-term care in nursing homes towards HCBS.

The Aging Strategic Alignment Project, under a cooperative agreement with the U.S. Administration on Aging, undertook a study of the states’ HCBS programs that specifically target older adults and adults with physical disabilities. Its purpose was to examine the structure and selected components of these programs, along with new HCBS initiatives and barriers to program expansion. The Administration on Aging’s interest was in gaining a broad understanding of the scope of all HCBS programs under various funding streams, the states’ infrastructure as a conduit for Older Americans Act funds, and the extent to which the aging network is positioned to expand the availability of community-based long-term care services and supports. The primary source of information for the study was the State Unit on Aging (SUA) in each state, a key player in the development and advancement of HCBS. The study explored services funded by five major revenue streams: Medicaid waivers, CMS-funded programs and grants, state-funded programs, Medicaid State Plans, and Title III of the Older Americans Act.

Information covering the period between January 2008 and January 2009 was collected using an approach that combined online and telephone interview methods. SUA directors, or staff they designated, first were asked to complete an online tool with questions about the basic components of their state’s HCBS programs, funded by the sources indicated above and serving older adults and adults with disabilities. This allowed each HCBS program to be referenced by name in follow-up telephone interviews aimed at gathering more detailed information on these programs. Staff from other state agencies involved in HCBS, such as Medicaid agencies, also were asked to provide information when the SUA respondent made referrals to them regarding programs and issues about which they were thought to be more knowledgeable. In other instances, staff from other agencies participated with SUA staff in phone interviews. Two states (Ohio and Kentucky) served as pilot sites to assess the utility of the online and telephone interviews. Excluding these
two states, the study ultimately involved 157 informants from 46 states and the District of Columbia (DC; will be referred to as a state hereafter to simplify reporting results) because of the breadth of information that was requested and the complexity of state governmental structures for managing HCBS. There were a total of 836 documented contacts with informants in these 47 states; two states (Hawaii and South Dakota) did not participate. Based on input from the states about HCBS programs as well as state-specific information, a profile was compiled for each state, and was then returned to all respondents in the state for verification. The additions and corrections that were provided were incorporated into the profiles and data used for analysis across states.

**HCBS programs by Funding Stream**

Detailed information was provided by 49 states about 217 HCBS programs under three revenue streams: 110 Medicaid waivers, 34 CMS-funded programs and grants, and 73 state-funded programs. In addition, all states have a Medicaid State Plan and Title III funds from the Older Americans Act that can be used to provide HCBS. Supplemental funding options for providing HCBS include: other Older Americans Act funds (reported by 42 states); local funds (37 states); and block grants, both Social Service Block Grants (30 states) and Community Service Block Grants (10 states). It should also be noted that 15 states reported that they are using managed care health plans for the administration and delivery of HCBS.

**Services Reported**

States’ reports revealed that they offer a broad array of services for older adults and adults with physical disabilities through HCBS programs under Medicaid waivers, CMS funding, state funding, Medicaid State Plans, and Title III of the Older Americans Act. These services were grouped into 21 categories for analysis purposes.¹

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**Figure 1**

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<tr>
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<th>Number of States</th>
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<tr>
<td>Case Management/ Care Coordination</td>
<td>49</td>
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<tr>
<td>Chore/ Homemaking</td>
<td>49</td>
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<tr>
<td>Home Health/ Personal Care</td>
<td>49</td>
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<tr>
<td>Transportation</td>
<td>49</td>
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<tr>
<td>Equipment/ Supplies/ Modifications/ Asst Tech.</td>
<td>48</td>
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<tr>
<td>Information/ Assistance/ Referral</td>
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<tr>
<td>Nutrition/ Meals</td>
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<tr>
<td>Adult Day Care/ Adult Day Health</td>
<td>47</td>
</tr>
<tr>
<td>Legal Assistance/ Financial Advice</td>
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<td>Mental and Behavioral Health Services</td>
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<tr>
<td>Employment</td>
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</tbody>
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¹ Source: 2016 National Confederation of PRIORC States report.
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As shown in Figure 1, all 49 states reported that they provide the following types of services under one or more of the funding streams listed above: caregiver services, including respite and educational services; case management or care coordination; chore or homemaking services; home health or personal care services; and transportation services. The least frequently reported (28 or fewer states) included other residential services, assisted living, mental and behavioral health services, and employment services. It is likely, though, that at least some of the states offer the latter services through other state agencies or departments that were not involved in this study (e.g., employment services through the Department of Labor or mental health services through the Department of Rehabilitation Services).

Data for all HCBS programs under a given funding stream in each state were combined in order to examine the services that states reported offering by funding stream. The patterns that emerged suggest that different types of funding may enable states to offer a broader variety of services and to maximize coverage to reach a greater number of consumers (see Table 1). Under Medicaid waivers, case management or care coordination is reported to be the most frequently offered service (49 states), while employment services are the least frequently reported (4 states). For CMS-funded programs and grants, personal supports for community living or transitioning are the most frequently reported (22 states), likely due to the fact that services for transitioning long-stay nursing home residents back to the community have been an important component of Money Follows the Person Rebalancing Demonstration grants to 30 states under the CMS funding stream since 2007. Legal assistance or financial advice is reported to be the least frequently

<table>
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<th>Service Provided</th>
<th>Medicaid Waivers</th>
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<th>State-funded Programs</th>
<th>State Medicaid Plan</th>
<th>OAA Title III</th>
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Most frequently offered under each funding stream
Least frequently offered under each funding stream
Funding streams offering broadest array of services
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offered service (1 state) under CMS-funded programs and grants. The most frequently reported service in state-funded programs was home health or personal care (34 states), while the least frequently reported was employment services (3 states). Similarly, the Medicaid State Plans’ most frequently reported service was home health or personal care (43 states). There were four services that were not reported anywhere in a Medicaid State Plan: information, assistance, and referral; legal assistance or financial advice; health promotion activities; and companion services and/or socialization activities. Information, assistance, and referral was the most frequently reported service under Title III of the Older Americans Act (48 states), and assisted living was the least frequently reported service (1 state). Overall, the most services reported across the greatest number of states were under Medicaid waiver funding, followed by Title III of the Older Americans Act.

Approaches for Facilitating Rebalancing

To complement the broad array of available services, states are using approaches such as Aging and Disability Resource Centers (ADRCs) and nursing home pre-admission assessment to rebalance long-term care, maximize options, and make consumers aware of alternatives to—and avoid—nursing home admission. Assistance with navigation through the multitude of HCBS is a primary motivation for the establishment of ADRCs or Single Points of Entry (SPEs). The Administration on Aging and the Centers for Medicare & Medicaid Services provided grants to 43 states and territories to develop ADRC programs beginning in 2003; in other areas, comparable SPEs were established through state initiatives. The role of ADRCs and SPEs is to simplify access by providing a single portal into long-term care services and supports, while enabling states to coordinate their systems of information, assistance and access. In addition, ADRCs and SPEs help consumers, including those with chronic conditions and/or disabilities, plan for and make informed decisions about long-term supports, both public and private, and receive timely services, by offering consumers information on a full range of options and alternatives to nursing home care. The status of ADRCs during the year 2008 were reported by the states as follows: three states had no ADRC or SPE; 28 states had an ADRC or SPE, but it was not statewide; 6 states had an ADRC or SPE that was becoming statewide; and 12 states had a statewide ADRC or SPE. These numbers are likely to increase in the states that did not have a statewide ADRC or SPE, with the help of $11 million in grants that were awarded in September 2009 to 49 states and territories to implement or expand ADRCs.

Another mechanism reported by some states to avoid unnecessary nursing home admissions is a nursing home pre-admission assessment process; in some states, it is used for both Medicaid and non-Medicaid applicants. The process involves an in-person assessment of an applicant’s functional eligibility by someone other than nursing home staff prior to long-term nursing home placement. It is an opportunity to have a third party determine whether alternative HCBS options might be feasible instead. The philosophy behind nursing home pre-admission assessment is that it is easier to avoid nursing home admission (and expenses) in the first place and enable an individual to remain living in the community than to reverse the sequence of events. If someone is admitted to a nursing home, it is difficult for them to transition back into the community, especially if the housing and other community supports they previously had in place are no longer available to them. Nursing home pre-admission assessment was reported by 29 states for Medicaid applicants, and in some of these states, the same process is used with all nursing home applicants, regardless of payment status.

Accomplishments, Initiatives, and Challenges

In response to open-ended questions about initiatives, accomplishments, changes and challenges affecting HCBS delivery systems in the recent past (between 2006 and 2007) and in the coming years (between 2009 and 2010), informants most frequently mentioned topics related to HCBS infrastructure, ADRCs/SPEs, and the economy or funding. With
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respect to infrastructure initiatives in the last two years, key state informants spoke mainly in positive terms. Examples of these infrastructure initiatives included completing a long-term needs assessment (Connecticut and Maine), changing procedures to reduce waiting lists (Indiana) and to expedite service delivery (Kansas), adjusting budget line items to preserve funding for case management services (Iowa), working to ensure sustainability of changes made in long-term care (Oregon), establishing formal coordinating mechanisms for delivery of HCBS (New Mexico), and creating a consolidated office for long-term care (Pennsylvania). Looking ahead, informants also mentioned anticipated infrastructure initiatives such as using advanced information system technology (Arkansas, Oklahoma, and Virginia), streamlining referral and assessment procedures (Delaware, Indiana, and Louisiana), enhancing the role of the Area Agencies on Aging (Idaho), and establishing a unified long-term care budget (Ohio).

On a less positive note, most comments concerning the economy or funding related to budget shortages and restrictions, added expenses, and the effect of these on consumers, especially among states interviewed in the latter half of 2008. Nevertheless, there were also a few reports of increased or supplemental funding for aging services and bipartisan support for maintaining current funding. Other concepts related to infrastructure development, ADRCs, and SPEs frequently were cited as state initiatives. Several informants mentioned that the process of establishing a ADRC/SPE required various state agencies to collaborate in new ways. One respondent noted that the collaboration between the Administration on Aging and the Centers for Medicare & Medicaid Services in establishing the ADRC program served as a model for similar efforts at the state level.

Money Follows the Person (funded through CMS), the Community Living Program (formerly known as Nursing Home Diversion, funded through the Administration on Aging), and Own Your Future (funded through AARP).

Conclusions

Given the Aging Strategic Alignment Project study’s broad perspective on HCBS across funding streams and programs, the wide variation found among states in their activities to expand HCBS and the organizational structures for managing them was remarkable. The apparent complexity, redundancy, and inefficiency in public service programs and spending within and across states can result in confusion for both consumers and providers. It also underscores the need for structural reform of the long-term care system (Ng, Harrington, & Kitchener, 2010) through consolidation, integration, and coordination of HCBS to achieve greater efficiencies.

To this end, it is important for state-specific information on rebalancing efforts to continue to be gathered and tracked systematically, and to link the effects of changes with outcomes that show evidence of rebalancing.

From another perspective, the results of this study also illustrate the breadth of efforts states are making to strengthen HCBS programs and the potential for increasingly comprehensive HCBS, which are key to ensuring the successful shift from nursing home care to home and community-based care. While there is a great deal of variation among states in these efforts, the states in this study ultimately seem to be pursuing similar goals and most are using multiple funding sources in creative ways to accomplish them. The hope is all the states will be receptive to innovations in HCBS program design, delivery, and management that hold promise for continued expansion and improvement. Examples include designing programs around individual needs rather than characteristics such as age or diagnosis, and integrating long-term care planning across state departments or divisions to yield more efficiently organized long-term care systems, services, and supports. In line with the
intent of the Older Americans Act, the aging network can be better prepared to meet the growing need for long-term care by ensuring that older adults, adults with physical disabilities, and their caregivers have a variety of high-quality, long-term care options, including HCBS, from which to choose.

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Endnotes
1. For more information on the types of services that comprised each category, see http://www.benrose.org/KPI/ASAP%20Report/Appendix%202-111609.pdf
2. See www.adrc-tae.org

References


There is little doubt that the U.S. long-term care system has been undergoing significant changes over the past two decades, including a steady and cumulatively dramatic increase in the proportion of Medicaid long-term care (LTC) dollars that go to home and community-based services (HCBS) compared to institutions. Specifically, Medicaid spending on home care has grown from a 13 percent share of all Medicaid long-term care expenditures in 1990 to a 24 percent share in 1998, to 40 percent in 2007 (Kaiser Family Foundation, 2001; Kaiser Family Foundation State Health Facts.org, 2009). This shift in Medicaid LTC expenditure patterns coincides with the growth of LTC options, especially the expansion of HCBS. These expanded options include Medicaid HCBS waiver programs, local tax levy-funded services, and state plan services.

The growth of home and community-based options is the result of a number of complex factors, including fiscal pressures to reduce reliance on the most expensive LTC option (institutional care), and consumer (including caregiver) demands for options that better reflect their preferences. The sharpened focus on consumer preferences, choice, and autonomy is embodied in the growth of consumer-directed home care programs, including the national expansion of the Cash and Counseling program. All consumer-directed programs are based on the principle that consumers have the right and the ability to determine their needs, decide how best to have those needs met, and evaluate the quality of the services they receive. In practice, consumer-directed HCBS typically allow participants to hire and manage their own workers, and to guide how their service dollars will be spent. Cash and Counseling is the most fully developed model of participant-centered HCBS; it began as a rigorously evaluated demonstration project, and continues to serve as the gold standard for full consumer empowerment. Articles elsewhere in this publication document the growth and effectiveness of that approach.

The cumulative effect of these two major changes in LTC—expansion of home and community-based options and enhanced choice and control for consumers—suggest a more consumer-centered system in which public expenditures now provide growing support for consumer-preferred, less restrictive, and less expensive options. As evident in the mission statements of many HCBS agencies, the goal of long-term care services is to help people stay at home living healthy and independent lives for as long as possible. Federal funding has helped to support these changes, and will pave the way for further transformation and balance in our LTC system. Funding from the Administration on Aging for enhanced community living, streamlined and person-centered access to services, and preventive health programs, and funding from the Centers for Medicare and Medicaid Services...
(CMS) for consumer centered delivery models such as Money Follows the Person and Real System Change, are good examples of important federal initiatives.

With reauthorization of the Older Americans Act (OAA) on the horizon, and recently enacted health care reform that includes significant implications for long-term care, the pace of transformation in our long-term care system may quicken in the very near future. The aging network—Area Agencies on Aging (AAAs), tribal organizations that serve elders, and State Units on Aging (SUAs) established as part of the OAA—has been taking its place at the center of community-based long-term care. The 629 AAAs, 243 tribal organizations, and 56 SUAs have continued to be driven by the OAA’s core mission and provide services outlined in the Act. And, these organizations have expanded their role in long-term care transformation, have participated in innovative programs that reflect and shape the future of long-term care, and have built partnerships and collaborations that strengthen the ability of their local areas to develop livable communities for people of all ages. Data from a 2008 national survey of all AAAs (with an 80 percent response rate) provide evidence of the expanding role of AAAs in long-term care systems and the innovations they have undertaken to support the transformation of the system so that it better supports older people and their families in their goals to live at home independently for as long as possible (Kunkel, Lackmeyer, Straker, & Markwood, 2009). Data used throughout this article is drawn from the 2008 national survey of AAAs and the related report.

It is important to point out that tribal organizations that serve elders in their communities, funded partly through Title VI of the OAA, are going through similar expansions of roles and responsibilities. Title VI organizations were surveyed later than the AAAs (in Fall 2009); a final report based on the results of that survey will be released in late spring of 2010, but data from that report are not included here.

### Expanding Role of AAAs in HCBS

One of the hallmarks of AAAs is their diversity. This variability derives from the reason that area agencies came into being: to assure a comprehensive and coordinated system of services at the local level. Flexibility and local responsiveness support the AAAs in their ability to develop their organizations, business practices, and service provisions in ways that allow them to respond to and anticipate the specific needs of the older adults in their communities. The agility required for an agency to respond to the changing needs of its community manifests in a high degree of variability across agencies, even though they share a common commitment to the principles of the Older Americans Act and its core services.

The specific role and functions of each AAA and how it views its efforts to provide services and meet needs are also based on this variability and local responsiveness. While there are differences in the ranking given to the various roles they play, the most commonly cited role of AAAs include advocacy, planning and coordinating services, information and assistance, leadership, partnership and collaboration, focal point for services, and assessing and meeting the needs of elders.

The capacity of AAAs to provide services and programs that meet the needs of their community members is made possible by the partnerships they form, funding sources they leverage, and the different populations they serve. All of these factors support the unique role AAAs play and their ability to provide services in effective and efficient ways.

### Partnerships

Partnerships and collaborations with federal, state and local entities have strengthened the capacity of AAAs to provide services to their...
The Role of the Aging Services Network in Balancing and Transforming... communities. Overall, AAAs have an average of 10 informal partnerships and five formal partnerships. The most common partnerships are with transportation agencies, Adult Protective Services, advocacy organizations, emergency preparedness agencies, and federal programs; over 80 percent of AAAs have partnerships with each of these entities. In addition, AAAs maintain partnerships with state and local Medicaid agencies, long-term care facilities, and charitable organizations (see Figure 1).

Funding Sources
Governed by the Administration on Aging, each state receives Older Americans Act funding to be distributed to each Area Agency on Aging as determined by state-specific formulas. State units and the AAAs make proposals and decisions about how OAA funding can be used to best provide services to the older population in their local communities. AAAs are very effective in expanding their ability to serve their communities by actively leveraging other funding sources beyond what they receive from the OAA. In fact, nearly all AAAs (99 percent) indicate that they secure funds in addition to the funding they receive from the OAA. On average, AAAs leverage funding from an additional six sources. Over 70 percent of AAAs receive funding from their state general revenue and other local funding. Other common sources of funding come from the Medicaid waiver program (56.8 percent), grant funds (53.8 percent) and consumer co-pay or cost share (53.2 percent; see Figure 2).

Though not available to all AAAs, some are able to coordinate services and extend their reach in their community long-term care systems through involvement in Medicaid waivers. Over half (56.8 percent) of AAAs indicate that they receive funding from a Medicaid waiver program. Of those who get at least some proportion of their budget from Medicaid, the average proportion of their budget from Medicaid is 21.2 percent, with a median of 12 percent and a range from one to 95 percent.

Serving Populations of All Ages and Targeting Diverse Populations
One of the important dialogues among professionals involved in long-term care policy and programs is the fragmentation of service systems by age of the person using long-term services and supports. There is growing interest in coordinating systems of care for people of all ages. In keeping with this trend, over 45 percent of AAAs indicate that they have made progress in expanding the target groups they serve; an additional 20 percent plan to work on this; and 8.3 percent already expanded to serve other groups in addition to older people, including children (ages 0 to 17 years) and adults who are younger than the OAA eligibility age of 60 years. When asked if they were the single entry point for different target populations in 2008 just over a quarter (25.4 percent) indicated that they were a single entry point for at least some services for children ages 0 to 17 years, 63.4 percent for adults ages 18 to 59 years, and 39.2 percent for all age groups; these proportions are a notable increase compared to 2007 (see Figure 3).

While the age groups receiving support from the aging services network are expanding, AAAs also are sharpening their focus on other target groups along a continuum of needs and resources, including those with the highest level of impairment and greatest financial need, and those who can afford to pay privately for some of their own services. The same AAA may have one client with a nursing home level-of-care need, and another client who can pay privately for minimal services such as a meal delivery or a ride to a doctor’s appointment. AAAs are able to assess and support the needs of both...
of these individuals and the range of individuals in between.

**AAAs and Long-Term Service and Supports Innovations**

In addition to the core services and supports offered by AAAs (including congregate meals, transportation, and information and referral), AAAs have expanded the services and programs they offer and are taking part in innovations designed to transform the long-term care system. In particular, AAAs are helping to promote streamlined access to integrated services and supports, enhanced community living (including consumer-directed services), evidence-based health promotion and disease prevention programs, and outreach to private-pay consumers.

**Role as the Single Point of Entry for Services (Including ADRC Models)**

There are several models for providing a single point of entry and streamlined access to long-term services and supports. These models can take different forms and can involve different partnerships and access points. Point-of-entry models that were investigated on the survey include: being part of a network of partners that all serve as consumer access points (e.g., “no wrong door”), operating as a single point of entry but coordinating with off-site partners for some eligibility determination and access-related functions, being designated as an Aging and Disability Resource Center (ADRC), operating as a single point of entry and providing all eligibility determination and access-related functions onsite, and operating as an Aging Resource Center (ARC). Just under half (45.2 percent) of all AAAs have made progress towards positioning their organization to be a point of entry for long-term care in their area, while another 29.6 percent already have their organization in this position.

In addition to serving as a point of entry into the long-term care system, AAAs have made efforts to improve how consumers access services. Just over two-thirds (68.7 percent) are involved in providing a seamless intake, assessment, and eligibility determination process for the consumer, and over 50 percent are involved in developing cross-agency data systems to share consumer and provider information.

**Consumer Direction**

As noted above, AAAs and the aging services network in general have become increasingly consumer-centered, using consumer input to guide the services and programs offered by their agencies. Over 90 percent of AAAs assess consumer satisfaction with their services, 81.3 percent ask consumers about their service preferences, and 63.7 percent assist consumers in directing their own services at some level. At the more extreme end of self direction, only 32.5 percent have made progress or have in place a mechanism for providing vouchers or other funding directly to consumers to purchase services.

Roughly half of all AAAs (48.4 percent) provide services to their clients with a consumer-directed option, whereby individuals have choice and control over the services and support they receive. This option gives individuals the ability to hire, manage, and dismiss their workers and the opportunity to plan and budget for services. Of that 48.4 percent who provide services with a consumer-directed option, 70.1 percent offer personal care, 69.3 percent offer respite care, 52.9 percent offer Family Caregiver Support Program, and 41.0 percent offer chore services. AAAs that offer consumer-directed services also offer options by which consumers can hire workers directly (86.7 percent), hire relatives (77.5 percent), have a representative to help manage responsibilities (61.3 percent), and purchase goods and/or services (52.5 percent).

Over half of those who offer services with a consumer-directed option have between one and 50 people enrolled in the program while another 30 percent have between 51 and 250 enrolled. Over 40
percent expect to increase the number of consumer-directed services offered over the next year.

**NH Diversion**

AAAs have expanded their roles in enhancing community living options by developing strategies and practices that help keep older adults out of nursing facilities and in their homes and communities for as long as possible. Just over 30 percent (31.4 percent) of AAAs currently participate in an Administration on Aging Nursing Home Diversion Modernization grant or have a formal nursing home diversion program.

Nearly 90 percent of AAAs give priority to consumers (in at least some services) with greatest impairment and to those who are at risk of being placed in nursing homes. In addition, 42.7 percent are involved in developing strategies to identify individuals at risk for spending down their assets in order to qualify for Medicaid.

**Health Promotion and Evidence-Based Programming**

There are a variety of disease prevention and health promotion services and programs AAAs provide that enable older adults to stay healthy and active in their communities. These services and programs include general health promotion activities, caregiver support programs, nutritional counseling and education, and medication management (see Figure 4). On average, AAAs provide six general programs related to disease prevention and health promotion services; these programs are not necessarily formal evidence-based training programs.

As shown in Figure 4, 55.6 percent of AAAs are involved in providing evidence-based programs to prevent and/or manage chronic disease or disability. Evidence-based disease and disability prevention programs are tested programs that have proven effective and have been published in peer-reviewed scientific journals. These AAAs use a number of formally recognized evidence-based programs such as Chronic Disease Self-Management, A Matter of Balance, EnhanceFitness, and EnhanceWellness.

**Private Pay**

AAAs also are expanding the services and populations they serve by reaching out to individuals who are able to share the cost or pay in full for their services. As mentioned above, 17.7 percent of AAAs reported that they receive funding from private-pay consumers, and 53.2 percent indicate that they receive funding from consumer co-pays and cost sharing. In order for AAAs to serve these populations effectively and efficiently, many are taking steps to reach out to these populations and develop policies and procedures that allow this service provision to happen. Nearly one-fifth (19.7 percent) of AAAs are involved in marketing to attract private-pay consumers and 21.2 percent are involved in building a billing system for private-pay consumers (see Figure 5).

**Conclusion**

The contours of the HCBS landscape are shifting based on demographic, economic, political, and cultural change. In this shifting terrain, the aging services network plays an increasingly central role in the provision of person-centered, community-responsive, long-term services and supports for diverse groups of consumers. In many specific and essential ways as documented above, AAAs are helping to transform the long-term care system so that it provides broader options, balances funding to be more in line with consumer preferences and abilities, and effectively supports people in their efforts to remain healthy and independent in their communities for as long as possible.

**Addendum: AAA Network on the Move**

The rapid increase in the aging population presents opportunities and challenges to the nation’s aging services network, requiring it to expand and enhance its operations in order to meet the growing needs of an unprecedented number of older adults and their caregivers for home and community-based services and supports. As data from the 2008 Area
Agency on Aging survey indicate in this article and in the report based on the survey (Kunkel et al., 2009), the national network of AAAs is responding to these opportunities and challenges by broadening both the scope of their services and the populations they serve. Although older adults remain the primary audience, many AAAs have expanded their reach to provide services and supports to persons of all ages with disabilities, veterans and their families, and grandparents caring for grandchildren. This is a network that is on the move and is well-positioned to tackle the nation’s needs for home and community-based services.

As described above, in their role as a local resource for information and an access point for long-term services, the vast majority of AAAs currently operate as the single point of entry (SPE) for older adults, and a growing number also serve as an SPE for other age groups. AAAs go beyond traditional heath promotion activities and over half now are involved in evidence-based programs to help consumers prevent and/or manage their chronic disease or disability. And, AAAs are involved highly in activities that give consumers choice and control over the services they receive. AAAs have expanded their efforts to connect people with home and community-based services so that they can avoid premature or inappropriate institutionalization through formal nursing home diversion programs and by targeting consumers most at risk of nursing home placement in at least some of their services. Over half (60.5 percent) facilitate the transition of consumers from institutional placements back into communities. AAAs also are critical resources that help consumers to plan for and address their long-term service and support needs through information and referral services (94.1 percent), outreach and educational sessions (89.9 percent), and options counseling (69.6 percent through AAA, and 33.4 percent through ADRC).

Although the majority of AAAs have a diverse funding base and only rely on OAA funding as portion of their budget (an average of 40.2 percent of total budget), the Act remains foundational to their missions. The reauthorization of OAA in 2011 provides the aging services network with the opportunity to build on the nation’s commitment and resources available to ensure that older adults have opportunities to age successfully at home and in their communities for as long as possible. With this commitment, the nation’s AAAs will continue to be a network on the move, poised to help millions of older Americans access the home and community-based services and supports they could need at some point in their lives.

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Endnote
1. As defined by the Administration on Aging, evidence-based disease and disability prevention programs have been 1) tested through randomized controlled trials and proven effective at improving and/or maintaining the health status of older people; 2) provided successfully by community-based human services organizations, using non-clinical workers and/or volunteers; 3) published in a peer-reviewed scientific journal; and 4) translated into practice and ready for broad national distribution through community-based human services organizations (http://www.aoa.gov/AoARoot/AoA_Programs/HPW/Index.aspx).

References


Strengthening the Direct Care Workforce: Preliminary Recommendations from a National Panel of Experts in Long-Term Care

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In 2008, the ad hoc Committee on the Future Health Care Workforce for Older Americans, under direction from the Institute of Medicine (IoM), published a report concluding that the definition of the workforce must be expanded. According to this report, the definition should encompass everyone involved in a patient’s care, including direct care workers (DCWs), such as nursing assistants and home care aides, and informal caregivers, referring to family and friends (Institute of Medicine [IoM], 2008). Their inclusion is essential because DCWs and family caregivers deliver most of the hands-on care that chronically ill and impaired adults receive, and are regarded as the backbone of the long-term care workforce (Noelker, 2001). Hence, any efforts to improve the health care workforce must include strategies that address the needs and interests of DCWs and family caregivers. The IoM Committee proposed a three-fold approach for retooling the health care workforce aimed at the following: increasing recruitment and retention; enhancing competency through education and training; and improving care delivery to ensure better outcomes for care receivers.

For more than 40 years, the aging network has helped to grow the long-term care workforce in order to expand home- and community-based services (HCBS), thereby affording choice in long-term care arrangements and supporting the independence of older Americans. The Administration on Aging (AoA) has led the aging network in these efforts. Over the years, it has taken a central role through Title IV (of the Older Americans Act) training initiatives to improve the workforce and also has overseen the expansion of services for family caregivers. AoA continues to seek new ways to enhance the capacity of both the direct care workforce and family caregivers to provide quality care. As part of this effort, it commissioned the Benjamin Rose Institute under a cooperative agreement to convene a national panel of experts on the long-term care workforce that would examine potential strategies and initiatives to achieve this end. The panel’s work was organized to address four areas of concern: the supply of DCWs and family caregivers, the readiness or capacity of these helpers to provide care, the retention of DCWs and family caregivers in their roles, and the quality or outcomes of their care. The panel’s work continues to evolve and this report highlights preliminary recommendations put forth by panel members that were convened to date.

Increasing the Supply of DCWs and Family Caregivers

Chief among the panel’s recommendations was the continued expansion of consumer-directed care programs in which persons requiring long-term care in the community can directly hire and pay their helpers, including family members and friends (see the articles in this issue by Simon-Rusinowitz and colleagues for details on consumer-directed care). This approach gives consumers more control over their care arrangements. It also provides family caregivers with much needed financial compensation, especially when their earnings in the paid workforce are diminished because of caregiving responsibilities or there are financial expenditures related to the care recipient’s needs. In fact, a recent national survey of family caregivers reported that their top preferences for programs or policies that would be most helpful to them were tax credits and payment for the care they give (National Alliance for Caregiving, 2009).

Other labor sources from which to draw DCWs that were suggested by the panel included immigrant populations, displaced workers over 55 years old whose jobs were lost in the current recession, and persons with developmental disabilities who could be trained as DCWs. Separately, it was widely acknowledged that the wages and benefits paid for
direct care work deter recruitment and retention efforts. For example, home care work is among the fastest-growing occupations in the nation; home care workers, however, earn on average less than 10 dollars an hour (Dawson, 2010). One panel member noted that DCWs frequently are not paid all of the wages they earn because labor laws aren’t enforced for these workers. Indeed, a recent investigation into violations of employment and labor laws in America’s cities showed that home care workers were frequent victims of overtime violations, off-the-clock violations, and meal break violations (Bernhardt et al., 2009). Consequently, a number of panel members endorsed advocacy for the enforcement of existing employment and labor laws to ensure protection for these workers.

In regard to approaches that might attract family members to caregiving roles, it was suggested that providing funds for home modification and additions would enable families to accommodate disabled relatives more easily in their homes. Similarly, it was recommended that funds are made available to allow families to purchase and receive training in the use of assistive devices and technology to facilitate bathing, lifting, transferring, and other care tasks, which make the work less physically demanding and safer for both the caregiver and care receiver.

**Improving the Readiness of DCWs and Family Caregivers to Function in Their Roles**

The panel members were unanimous in their endorsement of the expansion of training and education programs, improvements in the content, design, and delivery of these programs, and evaluation of their effectiveness for both DCWs and family caregivers. Indeed, the IoM panel on the healthcare workforce (IoM, 2008) and the new Patient Protection and Affordable Care Act (2010) feature expanded and improved educational curricula and training programs in geriatrics for workers in long-term care. Panel members noted that in decades past, AoA historically has supported specialized training programs in aging to educate professionals better in gerontology and long-term care. Future investment in these types of training programs for DCWs both can attract new people to the field of long-term care and ensure that those working in the field are properly prepared to perform their jobs.

According to panel members, special attention and advocacy efforts are needed to raise the federal and state training requirements for DCWs, specifically certified nursing assistants and home care workers; these requirements have not been amended since the passage of Omnibus Budget Reconciliation Act of 1987. As of 2009, there were 20 states that had not increased the entry-level training requirements from the OBRA-mandated 75 hours, while 13 other states and the District of Columbia changed them to require 120 hours or more (Paraprofessional Healthcare Institute, 2009). Panel members also noted that entry-level training for these workers should include more clinical experience for their skill development and a fuller understanding of the nature of the work. Peer-to-peer and mentoring programs were viewed as a valuable component of entry-level training programs. Regarding DCWs’ continuing education requirements, there have been calls issued over the past decade for improvement (i.e., increased hours) in the annual requirement of 12 hours and mandates for specific training content such as skills and techniques for person-centered care (U.S. Department of Health and Human Services, 2002).

Another widely endorsed recommendation by the panel was to design training curricula and programs around the core competencies necessary for the job, including interpersonal and team skills and techniques to foster the care recipient’s independence. Students for whom English is not their first language were seen as requiring special attention and adjustments to training curricula and programs. Partnerships were viewed as central to expanded and improved training programs, specifically with Workforce Investment Boards, high schools, community colleges, and labor unions. At the federal level, a partnership between AoA and the Centers for Medicare and Medicaid Services, along with the Departments of Labor and Education, could result in coordinated and sustained attention to training program initiatives that would ensure ongoing advances in the quality of the long-term care workforce.

The panel members also pointed out the necessity to meet the training needs of family caregivers, which would require substantial attention and a plan of action. As evidence of the need for family caregiver education, findings from a national survey showed that fewer than one in five caregivers interviewed reported receiving formal training for their role, and 78 percent said they needed
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more information on a variety of topics related to caregiving (National Alliance for Caregiving, 2009). One recommendation from panel members was to develop and test training models in which DCWs are prepared to educate and train family caregivers because both assist care receivers with personal care and daily living tasks. Conversely, family caregivers were seen as having a role in training DCWs because family members can provide workers with insight into the values, preferences, and unique interests of those receiving care, thereby helping to foster person-centered care.

Improving the Retention of DCWs and Family Caregivers

As previously noted, improvements in wages and benefits and career advancement opportunities would be significant incentives for persons to enter and remain in the direct care workforce. Advocacy efforts were suggested for improving wages and benefits through the Older Americans Act, Medicaid, and state funds.

Another suggested avenue to pursue for better retention is improved supervision of DCWs. There is, in fact, a substantial body of research that highlights the importance of good supervision for retention of DCWs (Noelker, Ejaz, Menne, & Bagakas, 2009); thus, several panel members referred to the need for improved management training programs for providers of long-term care services and supports. One panel member suggested that standards should be developed for the aging network related to supportive work environments and effective worker retention practices. Moreover, these same standards should be used as performance standards for AAAs.

It previously was noted that to support retention of family members in the caregiving role, they can be compensated by tax incentives and payment under consumer-directed care programs. Some panel members added a caveat, however, which was that better training programs for consumers and family caregivers are needed so that they can more effectively supervise direct care workers under consumer-directed care programs.

Programs and incentives that transition former family caregivers into the direct care workforce also were suggested by panel members. Yet, some panel members felt this was a limited pool because former caregivers are often burned out and, if they are looking for employment, are likely to be seeking more lucrative opportunities. There was greater consensus among panel members around the need for increased funding for caregiver services, particularly respite services. Major increases in funds for the National Family Caregiver Support Program also were called for and seen as critical to support family caregivers and help retain them in their role. Some suggested various approaches for supporting employed caregivers, including having geriatric care managers help caregivers develop strategies to support care receivers while caregivers are at work, educating employers about caregiving issues such as the importance of flexible work schedules, and expanding the Family and Medical Leave Act and other paid leave policies at the federal and state levels to promote wage replacement.

Improving Outcomes for Care Recipients and DCWs

Turnover among care providers was seen by panel members as detrimental to the continuity and quality of care for recipients. Panel members were clear that the development and implementation of standard approaches for tracking turnover and retention rates by AAAs and employers in the aging network are necessary to determine the actual extent of turnover and to identify the workplace and management practices associated with lower turnover rates. These practices should be publicized and disseminated throughout the aging network for replication.

Regarding the role of education and training programs for DCWs in fostering quality care, the panel members again underscored a focus on desired outcomes for care recipients which directly link to core job competencies that are instilled through enhanced training programs. As noted previously, the core competencies should be broadened to include training to achieve quality of life outcomes for care receivers, such as sustained independent living, empowerment, choice and control over their care arrangements, and engagement in the management of chronic conditions.

Several panel members pointed to the potential role of the aging network in achieving better health care outcomes for care recipients. Specifically, they called for the implementation of demonstration and evaluation research initiatives
that address the network’s role in preventing unnecessary hospitalizations and emergency room use (i.e., improved service system outcomes) through partnerships and collaborative programs linking AAAs with primary care physician practices and hospital systems.

The issue of the variable quality of home care provider organizations was raised in discussing care outcomes, along with the suggestion to implement a voluntary system of accountability related to service reliability, consistency in workers, worker training requirements, and consumer satisfaction. High-performance provider organizations should be recognized for their successful efforts, and consumers and family caregivers should be made aware of those with records of high performance.

Regarding outcomes for family caregivers, several panel members recommended the implementation of a standardized caregiver assessment process and its application throughout the aging network and AAAs nationwide. This approach would help to ensure that the service and support needs of caregivers were addressed. Furthermore, it was recommended that family caregivers receive an assessment by trained care managers whenever care recipients are discharged from the hospital to determine the caregiver’s ability to manage new or expanded care tasks related to the care recipient’s condition and post-hospital care. As a critical agent in a family member’s care, the caregiver’s capacity at the time of discharge has a direct bearing on the relative’s successful transition back to and continued functioning in the home setting.

Conclusions

The panel members set forth a wide variety of programmatic, advocacy, and policy suggestions for the aging network’s consideration as it works to improve the supply, readiness, retention, and outcomes for DCWs and family caregivers. Going forward, this preliminary list will be discussed and refined by the full panel of national experts. The preliminary responses summarized in this report are indicative of the work that needs to be planned and implemented in order to equip fully the aging network as it expands home and community-based long-term care programs and continues to build and support the direct care workforce that delivers the bulk of long-term care.

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References

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The Benefits of Consumer-Directed Services for Elders and Their Caregivers in the Cash and Counseling Demonstration and Evaluation

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Significant challenges to the current long-term care system (e.g., rising health care costs, the growing number of aging baby boomers, shortages in the direct-care workforce) have policymakers searching for solutions to meet the long-term care needs of elders with disabilities. Consumer-directed (CD) models of home care (also called participant-directed and self-directed) such as Cash and Counseling offer elders who desire this option more flexibility and satisfaction than agency services, and the opportunity to delay or avoid institutionalization and remain in their homes and communities. Yet, some policymakers and others question the appropriateness of CD services for older consumers, often citing fear for their safety as well as beliefs that they would not be interested in CD services or willing/able to perform required tasks. This paper draws on extensive evaluation findings to address their concerns, move beyond ageist assumptions, and inform new health care reform policy decisions.

The Cash and Counseling Demonstration and Evaluation (CCDE) tested an innovative approach to providing personal care services; it offered Medicaid consumers of all ages in Arkansas, Florida, and New Jersey a cash allowance (of comparable worth) in lieu of agency-delivered services. The evaluation compared cost, quality, and satisfaction for consumers who received traditional personal care services versus those who received a flexible budget and were able to decide who would provide these personal and essential services, as well as when and how they would be provided. Counseling and bookkeeping services were offered to help consumers manage their monthly budgets and program responsibilities as they took on the role of employer. CCDE consumers were highly satisfied and between 85 and 98 percent said they would recommend the program to others (Schore, Foster, & Phillips, 2007). Compared with traditional agency services, CCDE consumers reported more flexibility and control, greater satisfaction with overall quality of life, and no greater adverse events on 11 health measures. These measures included whether the consumer: fell; saw a doctor because of a cut, burn, or scald; was injured while receiving paid help; had contractures develop or worsen; had bedsores develop or worsen; had shortness of breath develop or worsen; had a urinary tract infection; had a respiratory infection; was in poor health; and was hospitalized or in a nursing home during the previous two months (Carlson, Foster, Dale, & Brown, 2007). Reports suggest that CD care is successful not only for individuals with physical disabilities, but also for those with dementia (Tilly, 2007) and other mental health diagnoses (Shen, Smyer, Mahoney, Loughlin, Simon-Rusinowitz, & Mahoney, 2008). Although the CCDE demonstrated positive outcomes for consumers of all ages, some policymakers and stakeholders remain skeptical about the appropriateness of CD programs for elders. This service delivery option for older persons continues to have important policy implications for consumers, their family members, policymakers, and others.

What the CCDE Tells Us About Elderly Consumers and Their Caregivers

In the initial evaluation of the experiences of elders in the CCDE, evaluators examined survey
results for participants over age 65 in Arkansas and New Jersey, and over age 60 in Florida, to assess unmet needs and satisfaction with life. In almost every state and age group, these older Cash and Counseling participants were much less likely to report unmet needs, and much more likely to report significant increases in satisfaction with paid caregiver help, overall care arrangements, and with the ways they were spending their lives. Participants received more hours of paid care but still received significant hours of informal care. With regard to measures of adverse outcomes, CCDE evaluators summarized results for all age groups, including elders, and reported that “none of the 11 measures of health problems or adverse events examined showed worse outcomes for the treatment group than the control group, for any of the seven state–age groups…”

Furthermore, for nearly one-third of the 77 comparisons, the treatment group was significantly less likely to experience health problems. The significant differences revealed no consistent pattern across measures, age groups, and states, but they were sizeable, ranging from 20 to 50 percent of control group means” (Carlson et al., 2007, p. 479).

Evaluation of older CCDE consumers’ experiences has continued in secondary analyses, drawing on multiple data sources to provide in-depth understanding of their views about a CD cash option. Our most recent analysis focused on health-related outcomes in relation to specific age groupings. The sample of survey respondents consisted of 4,037 participants divided into three age groups; approximately 21 percent were aged 50 to 64 (10 percent in Cash and Counseling and 11 percent in agency services); 41 percent aged 65 to 79 (21 percent in Cash and Counseling and 20 percent in agency services); 38 percent aged 80 and older (18 percent in Cash and Counseling and 20 percent in agency services). These age categories represent pre-retirees, young-old, and old-old as reflected in the literature. This stratification allows us to look at aging baby boomers as a distinct group. The caseload consists of more young-old and old-old individuals, with fewer pre-retirees in the home and community-based services (HCBS) programs studied. We developed multivariate regression models that controlled for demographics and baseline characteristics.

**Satisfaction with Care**

Results from this analysis of participants over age 50 mirror those found in the overall CCDE evaluation. In all three age groups, older CCDE beneficiaries were more satisfied with their care compared to those receiving agency services. Older CCDE participants reported significantly higher satisfaction with life, paid care arrangements, help around the house, and transportation as compared to those receiving traditional services. Improved satisfaction with transportation is an important finding as home care agency workers often are not allowed to provide this service (along with administering medication) due to liability issues. The ability to match consumer preferences to the desired services is likely to have improved their satisfaction with care. The magnitude of the positive effects tended to decline with age. Yet, we still found a high level of satisfaction with transportation, arrangements of paid care, and paid help around the house for the oldest age group—those age 80 and over.

**Health Outcomes**

Survey results also demonstrated no increase in adverse events in the CCDE program in older populations. We found no effect on self-reported overall health status. The oldest consumers (age 80 and above) in the CCDE program had a lower chance of developing or worsening contractures or developing shortness of breath. The youngest group (age 50-64) had a lower chance of staying overnight in a hospital or nursing home. These results indicate that care provided in the CCDE may, in fact, improve health or at least help to avoid further declines in health.

**Qualitative Interview Results**

To continue the focus on older age groups, we also examined data from qualitative in-depth
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interviews conducted by University of Maryland, Baltimore County (UMBC) researchers during the CCDE. The interviews were conducted between March 2000 and August 2002 as part of a larger UMBC study of cash option participants in Arkansas, Florida, and New Jersey CCDE programs. The ethnographic study examined 76 care teams in these three states, with each team composed of one consumer, one representative, one paid caregiver, and a consultant. The in-person interviews were conducted in the consumers’ homes and were semi-structured, open-ended, and lasted 60 to 90 minutes. The qualitative study examined how each care team worked together to provide insight into choices made by the consumer and challenges posed by participation in the CCDE (San Antonio, Simon-Rusinowitz, Loughlin, Eckert, & Mahoney, 2007). Of the 76 original ethnographic stories, 45 represented consumers age 50 or older: 10 from Florida, 17 from New Jersey, and 18 from Arkansas. We selected age 50 as the cutoff point to maintain consistency with the quantitative analysis, and examined the interview data regarding health outcomes and satisfaction with care.

The CD approach gave elderly individuals with disabilities feelings of autonomy, well-being, and independence. Consumer teams in all age groups expressed overall satisfaction with the CCDE in terms of being able to direct their finances and choose goods and services that best fit their individual needs. These benefits allowed some older participants to do things they could not do before, and others were able to remain in their own homes longer. Consumer teams reported that trusted family and friends were more dependable and responsible than previous agency workers. Many were more confident that caregiving tasks would be completed. Elderly consumers enjoyed peace of mind and reported that they felt safer and better taken care of by family or known caregivers whom they selected. Some consumer teams described better family relationships because of the program. Many caregivers were able to anticipate consumer needs and take action before problems arose; “Since he is a renal dialysis patient, he receives treatment several times per week early in the morning. To accommodate his needs, Barbara comes each morning between 5:00 to 7:00 to prepare his breakfast” (AR Consumer Team); “I prefer her. It is the trust. To give me a bath and everything” (NJ Consumer Team).

The qualitative analysis indicated no age differences among consumers in their overall satisfaction with the flexibility of the program or with their relationships with their caregivers, although we noted some differences in responses among the age groups. Younger consumers (ages 50 to 64) mentioned satisfaction with the program consultant more often and feeling confident that caregiving tasks would be performed. They also reported feeling more autonomous with the program and expressed enjoyment about controlling their own services. A good relationship or friendship between consumer and caregiver was mentioned more often in the 50 to 64 year and 65 to 79 year age groups versus those in the 80 and older age group. Consumers in the 65 to 79 year and 80 and older age categories mentioned more than younger consumers that they felt safer with their caregiver and less fearful for their personal safety when their caregiver was present. Consumers over age 65 felt that their caregiver was concerned about them and consumers over age 80 spoke more often about caregivers addressing private or intimate needs. Some younger consumers discussed dissatisfaction with their caregiver while no consumers over age 80 mentioned dissatisfaction with a caregiver. Although these data are limited by small numbers of consumer teams, findings suggest that the focus of satisfaction with the CCDE was slightly different for the three age groups and represented a shift from concerns about autonomy and control (for the younger age groups) to concerns focused more on intimacy, privacy, and safety (for the oldest seniors); “Roger explains it, ‘I can look in his eye and know what is going to come.’ Roger feels that the most important thing he does for his father is to protect him” (FL Consumer Team).

Despite high levels of overall satisfaction, consumer teams also noted areas of dissatisfaction with the cash option. Several consumers in each age category mentioned dissatisfaction with the amount of money or number of hours of care they received...
with the program. Some of these same consumers expressed dissatisfaction with other aspects of the program, such as difficulty understanding the program, contacting the program consultant, or finding and scheduling caregivers. Programs were able to use these findings to address areas of dissatisfaction.

**Caregiver Well-Being**

Caregiver burden can have negative consequences for the health of both caregivers and consumers and may result in earlier nursing home placement for consumers. We sought to determine if informal and paid caregivers for older consumers also have been satisfied with and benefited from their roles in the CCDE. Similar to findings from the original evaluation, informal caregivers for CCDE participants in the 50 to 64, 65 to 79 and over 80 age groups were more satisfied with life and arrangements for client care, and experienced less physical, emotional, and financial strain as compared to informal caregivers for participants who received traditional services. In the qualitative interviews, they spoke about the program flexibility and how that helped them manage multiple responsibilities. For example, families could schedule coverage during work hours (even non-traditional work schedules) and during other responsibilities to allow them to manage caregiving with child care and college classes. Informal caregivers in the CCDE program were less worried about the client’s care or safety. They spoke about the peace of mind that came from the ability to hire their own workers (e.g., relatives, friends, others) whom they trusted to provide high quality care.

“Informal caregivers in the CCDE program were less worried about the client’s care or safety. They spoke about the peace of mind that came from the ability to hire their own workers (e.g., relatives, friends, others) whom they trusted to provide high quality care.”

Although the contrast in the survey responses for paid-directly hired workers versus agency workers was not as striking as for the informal caregivers, the direction of the effects were similar (i.e., CCDE directly hired workers (most of them family or friends) reported equal or less physical and emotional strain and equal or better relationships with clients as compared to agency workers); “Sylvia…feels that she can do a better job [in a CD setting]…. I’m happy. It’s better pay. I’m more relaxed. I don’t have to worry about getting a phone call [from the agency] every 15 minutes to go here and go there….the job is friendlier….It’s like being in my own family. This is what I try to tell the girls [at the agency who burn out]” (FL Consumer Team).

Findings from the ethnographic study clearly demonstrated the importance of paid and unpaid workers functioning as a team to care for a consumer. When these relationships were coordinated everyone benefited—consumers received better care, and both paid and informal caregivers experienced decreased emotional strain and worry.

These analyses should help to address persistent concerns about the interest and ability of elders to manage a CD personal care option. Evidence from the survey and ethnographic study analyses indicates that older CCDE consumers generally were satisfied, experienced enhanced well-being and no increases in adverse effects, and that informal and paid caregivers benefitted as well. While a CD model of personal care services may not be the choice of every consumer, our analyses suggest that it should be one option among others for all consumers, including elders.

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Endnote
1. A substantial number of informal caregivers identified at baseline were subsequently paid for their work. Payment most likely contributed to their increased satisfaction and decreased strain. For example, in their further analysis of similar treatment effects for Arkansas Cash and Counseling informal caregivers for clients of all ages, Foster, Brown, Phillips, & Carlson (2005) concluded that “estimated program effects were not driven solely by a payment effect, but payment may have contributed to the magnitude of the impacts” (p. 481).

References


What Does Research Tell Us About a Policy Option to Hire Relatives as Caregivers?

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Meeting the long-term care needs of the growing aging population is a priority policy issue in the United States. Even as public resources become more limited and policymakers seek to target areas of waste, fraud, and abuse to trim program budgets, participants today demand and expect more flexibility and responsiveness in public services. We need imaginative solutions to address the challenges created by the combination of a growing number of elders and people with disabilities and a limited long-term care workforce. The traditional model of home and community-based services emphasizes professional decision making and agency oversight, and imposes rules and restrictions regarding the timing, duration, amount, and scope of services. In contrast, participant-direction (PD; also called consumer-direction [CD] and self-direction [SD]) is a service model that offers elders and persons with disabilities more control over their services. Cash and Counseling, one of the most flexible models of PD, allows participants the authority to manage a personal care budget, hire, supervise, and fire their own personal care workers (including relatives), and purchase other personal assistance goods and services. While some speak about CD and hiring relatives as if they are one and the same, not all CD programs include this option.

Participant-direction has become increasingly appealing to policymakers and others who view it as a way to empower participants, improve care, and stretch scarce resources. Opponents of hiring relatives as caregivers, however, have raised concerns, especially about the option of hiring legally responsible relatives, such as parents and spouses of people with disabilities. They question whether hiring relatives who otherwise might provide service to loved ones for free is an appropriate mix of public-private responsibility. They have raised concerns about the quality of care elders and people with disabilities may receive, and the potential for fraud and abuse. They also fear increased public costs if the unpaid care hours that currently are provided to participants by friends and relatives were substituted with paid care. Proponents of the option to hire family members as caregivers have cited benefits such as expanding the worker supply to compensate for the limited and decreasing pool of workers, increasing participant choice, and improving the quality of care that participants receive.

“The ability to choose and hire workers, including family members, enhanced not only quality of care, but also the participant’s ability to receive paid care at all.”

This article highlights new information that can inform the long-standing policy debate about hiring relatives as caregivers (Linsk, Keigher, Simon-Rusinowitz, & England, 1992; Simon-Rusinowitz et al., 2010; Simon-Rusinowitz, Mahoney, Loughlin, & Sadler, 2005). Rather than relying on long-standing fears and myths, a synthesis of existing research about this key policy option can inform difficult state program and budget decisions as well as national health care reform policy choices. In particular, these findings can guide policymakers as they determine how to implement the Community Living Assistance Services and Supports (CLASS) provisions in the new health care reform legislation.

The Cost of Long-Term Care

More than 8.6 million community-living adults over age 65 need assistance with one or more activities of daily living or instrumental activities of daily living. The cost in 2003 for each nursing home patient was estimated to be $66,000 per year (Congressional Budget Office [CBO], 2004). This is about three times...
higher than individual costs for community residents, and differences in the level of care needs between community-living individuals and nursing home patients do not account for the significant difference (Kaye, Harrington, & LaPlante, 2010).

Over 10 million individuals receive care at home from unpaid caregivers. The estimated 29 million unpaid caregivers are typically female and either spouses or middle-aged daughters of the care recipients (Institute of Medicine [IoM], 2008). The economic value of unpaid help is over $300 billion dollars per year (AARP Public Policy Institute, 2008; Iglehart, 2010). The role of unpaid or informal caregivers will continue to grow with the increasing aging population and the number of individuals with unmet needs also will continue to grow. Individuals with disabilities who live alone without family help are at risk for having unmet healthcare needs. It is difficult to project the future cost of long-term care for elders with disabilities, especially since the location of this care and who provides it are important factors. Kaye et al. (2010) suggest that a redistribution of care, from institutional and agency to non-institutional and individual providers, will result in the greatest decrease in long-term care spending.

The issue of cost in public services also is integrally tied to the question of whether people actually receive services. A program that provides immediate service inevitably will cost more initially than a program in which those entitled to service linger on waiting lists. Since more than half of Cash and Counseling participants opted to hire relatives, this likely explains some increased ability to obtain personal care services. When comparing program costs, we must acknowledge that a key program benefit—increasing timely access to services—may lead to increased initial program costs. Cash and Counseling Demonstration and Evaluation (CCDE) evaluators concluded that “Medicaid costs [for personal care services] were generally higher under Cash and Counseling because those in the traditional system did not get the services they were entitled to.” (Dale & Brown, 2007, p. 488). They noted, however, that it is unlikely that policymakers would seek to contain costs by depriving beneficiaries of necessary services.

Even in early stages of program implementation, CCDE evaluators found evidence of potential long-term cost savings, from reduced use of other Medicaid services, such as nursing home care and/or skilled home health services (Dale & Brown, 2007). By the third year of implementation in Arkansas, their Cash and Counseling Program, “IndependentChoices” had reduced nursing facility use by 18 percent over the three-year period. Follow-up cost evaluations conducted in Arkansas have shown that Cash and Counseling reduced overall Medicaid program costs and produced savings of over five million dollars over the first 10 years of implementation (Arkansas Department of Human Services, 2008).

A recent analysis of California’s In Home Supportive Services (IHSS) Plus waiver program provides additional information about the costs of hiring legally responsible relatives as caregivers. In this analysis, Newcomer and Kang (2008) compared recipients having a waiver-eligible provider (i.e., parents of children, spouses of adults) for any portion of 2005 with recipients in the regular IHSS program who received personal assistance services through other relatives and non-relative providers. The researchers found “no financial disadvantage and some advantages to Medicaid from allowing spouses, parents (and other relatives) to be paid IHSS providers.” Their research “argues in favor of honoring the recipient’s and family’s preference for such providers” (p. 42). They also suggest that the preference for family caregivers in this program may continue to grow, due to the increase in enrollment of Hispanic and Asian populations who are more likely to select the option.
What Does Research Tell Us About a Policy Option to Hire Relatives as Caregivers?

Shortages in the Direct Care Workforce

A 2008 Institute of Medicine (IoM) report outlined policy issues related to long-term care workforce shortages and deficiencies (including health care professionals, paid, and unpaid direct care workers). The report suggests that the direct care workforce is not sufficient to meet the demand, and this problem will grow as more elders with disabilities shift to using home and community-based services. Low salaries, minimal benefits (i.e., health insurance and sick leave), and lack of flexibility are some of the factors associated with the high turnover rate (80 to 90 percent turnover within the first two years) of direct care workers. Low employee retention and inadequate training often lead to poor quality care. Suggestions to reform long-term care and ensure an adequate and skilled workforce include: increasing recruitment and retention efforts, providing workforce education and training, increasing financial incentives to make jobs more competitive, and redesigning services to be more effective and efficient.

The IoM identified three key principles for redesigning long-term care services:

• The health needs of the older population need to be addressed comprehensively;
• Services need to be provided efficiently; and
• Older persons need to be active partners in their own care.

The report also explored several care delivery models, including Medicaid Demonstration Projects, considered as innovative in their efforts to reduce workforce shortages. Cash and Counseling is a CD model that addresses these key principles. The program evaluation has shown positive results in improving care coordination while allowing individuals to participate in selecting services.

The critical shortage of direct care workers in the U.S., combined with our aging population, highlights the crucial need for expansion of the direct care workforce. Proponents of hiring relatives as caregivers have suggested that the option may provide entry into the field of home health care for people who may not have otherwise considered this career option. Thus, the option to hire relatives as caregivers offers exciting possibilities not just for the care of one participant, but for expanding the pool of personal assistance workers for all participants. The critical question, however, has been: will workers who gain experience caring for a family member remain in the home health care field?

A recent study addressed this by surveying caregivers who previously had been employed through IHSS caring for a friend or relative (Benjamin, Matthias, Kietzman, & Furman, 2008). The study compared 180 caregivers who had remained in the home health care field after their IHSS experience (“stayers”) with 203 who had not stayed in the field (“leavers”). The authors estimate that about 5 percent to 10 percent of IHSS family caregivers remain in the field to care for others after their initial caregiving experience. In addition, even in the absence of targeted retention efforts, the proportions of leavers who said they were willing to care again for family (59 percent) and for strangers (43 percent) was encouraging for states looking to expand their direct care workforces. These findings suggest that former family caregivers could be targeted for recruitment as professional caregivers, and that family caregiving has the potential to increase significantly the direct care workforce. The researchers concluded that “the growing number of programs that pay family members to provide home-based services are attracting relatives and friends who had not considered home care as a career option. With more outreach … about home care employment options, these related workers may help solve the long-term care workforce shortage problem” (p. 104).

Participant Preferences, Quality of Care, and Substitution of Care

More than 6,500 Medicaid consumers in Arkansas, Florida, and New Jersey participated
in the Cash and Counseling Demonstration and Evaluation (CCDE)—a real world test of this model in which volunteers were randomized to receive either traditional agency services or PD services. More than half of participants that were given the option to hire their own worker opted to hire relatives to address unmet personal care needs (including legally responsible relatives such as parents of children with disabilities in Florida and spouses in Florida and New Jersey). CCDE evaluators addressed the issue of quality of care and concluded that “the control and flexibility offered by the program greatly increased consumers’ satisfaction with the help they received and with their overall quality of life. Consumers under Cash and Counseling appeared to receive care at least as good as that provided by agencies, in that they had the same or an even lower incidence of care-related health problems” (Carlson, Foster, Dale, & Brown, 2007, p. 480-81). In a further analysis that compared satisfaction with directly hired related versus non-related workers in Arkansas, researchers found that participants who hired relatives reported that they were more satisfied with their care, reported fewer adverse health effects, were more likely to receive care during non-traditional hours and reported less unmet need for personal care as compared to those who hired a non-relative personal attendant (Simon-Rusinowitz et al., 2005).

The ability to choose and hire workers, including family members, enhanced not only quality of care but also the participant’s ability to receive paid care at all. For example, in New Jersey, for the two weeks prior to the nine-month follow-up survey, 92 percent of cash option participants ages 18 to 64, and 94 percent of cash option participants age 65 and older were receiving paid care. For those participants who were randomized to receive agency services, the corresponding percentages representing those who received any paid care were 79 percent and 82 percent respectively. The magnitude of this effect depended on the availability of directly hired workers versus agency workers, and was most pronounced in Arkansas, due to worker shortages. On average, participants who relied on paid agency services received fewer hours of paid care and slightly more hours of unpaid care. However, for both Cash and Counseling participants and those randomized to receive agency services, family members and friends continued to provide for their loved ones; 90 percent or more of consumers in both groups in every state and age group continued to receive some unpaid care at nine months. For the two-week period prior to the nine-month evaluation, the number of volunteer care hours provided for Cash and Counseling participants was quite impressive, with averages ranging from 74 hours of unpaid care received by non-elderly participants in Arkansas to 148 hours received by non-elderly participants in Florida (Carlson et al., 2007).

Lack of Research Support for Concerns about Fraud and Abuse

Cash and Counseling does not screen participants for inclusion or exclusion, but has several built-in mechanisms to track service quality and to help prevent fraud and abuse, that is, to protect the participant as well as program integrity. (Not surprisingly, approval of Medicaid waiver applications requires a strong program design emphasis on preventing fraud and/or abuse.) These checks and balances apply to all participants, not just those hiring relatives. A bookkeeping service writes checks to workers and pays taxes, allowing participants to direct the use of their allowances without managing large cash amounts. A participant-designated representative helps those consumers who need and/or prefer assistance with employer tasks such as hiring and supervising workers. Consultants help develop and approve cash plans, and monitor participant well-being. Consultants also are responsible for reporting suspicious cases, which includes notifying the program office and/or an adult protective services agency. If a consultant is concerned about a difficult family relationship with a paid family worker, the consultant can increase monitoring, help the participant change workers, or ask the participant to return to agency-delivered services.

The CCDE evaluation found that these built-in mechanisms were effective, and fraud and abuse were not major concerns.
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not major concerns. Phillips et al. (2003) reported that “instances of exploitation of consumers who were already receiving the allowance were rare in the three Cash and Counseling programs. Those that did occur were resolved” (p. 32). In addition, CCDE survey data indicated that Cash and Counseling participants were less likely than those randomized to agency services to report problems with their caregivers, such as neglecting them, being disrespectful, and taking things without asking (Carlson et al., 2007).

Participants and caregivers provided additional information in focus groups and in-home interviews. Consistent with the CCDE survey data, the interview data revealed no evidence of family caregivers who abused or neglected participants. To the contrary, participants described closeness, loving care, and trust as a part of the care they received. For example Mrs. Williams is an 85 year-old African American woman who lives with and is cared for by the youngest of her four daughters. Three of her four daughters live nearby and help in her care. They care for Mrs. Williams because “it’s basically a family thing… I can remember the time she used to walk to work, she did housekeeping. … she provided for us and let herself go, and now is our time to try to help her as much as we can. Because I can remember times she made sure we had shoes and she was putting cardboard in the bottom of her shoes to make sure we had them. It’s our time to see that she gets what she needs” (p. 154). Family caregivers were very dedicated, often worked more hours than were paid for, and used their pay to buy items for the participant. Participants and caregivers often spoke of the friendship or affection they shared (Eckert, San Antonio, & Siegel, 2001).

“...argues in favor of honoring the recipient’s and family’s preference for such providers.”

Many caregivers reported feeling blessed or lucky to be able to provide care to a loved one. For example, one Arkansas caregiver stated: “I just feel good that I’m able to be there for her right now” (Simon-Rusinowitz et al., 2005, p. 100). When asked about the challenges of being a paid caregiver, participants acknowledged the time demands of this difficult role, and the ways in which it limited their family and social lives. Overall, however, they appeared to accept these challenges and were happy to care for their loved ones. A statement drawn from focus groups with paid family caregivers summarizes their experiences and confidence in caring for their relatives: “we’ve had these family members all these years and we know what has to be done on a daily and hourly basis” (p. 101).

Conclusion

Creating public policy to provide high quality and accessible home care services is a critical responsibility. Policymakers and other stakeholders are wise to proceed cautiously when creating policy for our most vulnerable citizens. Recent research results about the desirability, quality, and cost-savings of hiring relatives as caregivers, however, support the view that this option is an important component of long-term care policy. These substantial research findings can replace long-standing fears about this option and guide policymakers and other stakeholders when making tough state budget decisions and deciding how to implement new national health care reform legislation.

“The researchers found ‘no financial disadvantage and some advantages to Medicaid from allowing spouses, parents (and other relatives) to be paid IHSS providers.’ Their research ‘... argues in favor of honoring the recipient’s and family’s preference for such providers.’”

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References


Can Elephants Learn to Dance? Ohio’s Efforts to Create a Balanced System of Long-Term Services and Supports

Robert Applebaum  
Shahla Mehdizadeh  
Suzanne Kunkel

During the early days of computers, the founder of Apple was rumored to have said that the corporate giant IBM will develop a personal computer when elephants can dance. The analogous speculation in long-term care is whether big states with substantial investments in institutional care can bring some balance into their systems. Using Ohio—with the 7th largest aging population in the nation—as a case study, this paper explores whether and how a large state can create a balanced long-term system of services and supports. Based on typical long-term care balance indicators, Ohio is classified as having significant reliance on nursing homes (i.e., a large supply of nursing home beds per capita), heavy utilization rates of nursing homes, and high Medicaid nursing facility reimbursement rates (all in the top 10 in state rankings). At the same time, the state ranks in the bottom third in terms of balanced distribution of Medicaid long-term care expenditures, with a higher ratio of nursing home to home care expenditures (AARP, 2009; Burwell, Sredl, & Eiken, 2008). Ohio is one of two states in the nation in which the Medicaid reimbursement rate for nursing facilities is the responsibility of the legislature rather than the administration. In combination with a growing Medicaid program that accounts for almost one-quarter of the entire state budget, a rapidly growing older population, and a struggling economy, Ohio faces overwhelming long-term care challenges. In fact, budget projections suggest that without changes to the current system, Medicaid could account for more than one-third of the state budget by 2020 (Mehdizadeh, 2009).

A number of small- to moderate-sized states, such as Oregon, Wisconsin, New Mexico, Vermont, and Washington, have undertaken successful major reform efforts. Larger states, such as Ohio, Pennsylvania, Michigan, Illinois, and New York, have had a much more difficult time designing and implementing meaningful long-term care reform. For example, Ohio has almost 100,000 licensed nursing home beds, compared to about 9,000 in Oregon, which makes major changes politically and economically complicated. Ohio’s past, recent, and planned approaches to providing long-term services and supports serve as a case study to document both opportunities and challenges to large-state reform.

Ohio’s Change Efforts

For more than two decades, advocates and policy makers have worked to alter the state’s long-term care approach. We classify Ohio’s reform strategies into three major categories. First, the state has engaged in a series of incremental steps to modify the long-term care system for older people with disabilities, including: development of a nursing home pre-admission review assessment process along with a moratorium on nursing home bed construction (in 1994); a major expansion of its home and community-based Medicaid waiver program (in 1999, 2005, and 2007); and development of two Program of All Inclusive Care for the Elderly (PACE) sites (in 2002). Second, in 2006, the governor appointed a blue-ribbon committee to create a Unified Long-Term Care Budget and System for the state. The committee was charged by the governor to reform the system of long-term services and supports. Finally, in 2009, the state passed legislation that incentivized the Department of Aging and the area agency network to be more aggressive about nursing home diversion and transition activities in order to decrease the use of facility-based care.

The Effects of Ohio’s Incremental Change

Since the mid-1990s, Ohio has attempted to restrict nursing facility use and to expand home and community-based services (HCBS). To control nursing home use, the state placed a moratorium on new nursing home beds and required all applicants to nursing facilities to complete a pre-admission review prior to entry. These reviews are administered by the Area Agencies on Aging (AAAs), which also manage the home and community-based waiver program for
individuals age 60 and older. On the services side, the state grew its HCBS program (PASSPORT) from 4,500 to 28,000 individuals, developed a self-direction waiver (Choices) that now serves 550 individuals, developed a Medicaid Assisted Living Waiver Program that serves 2,000 participants, and was involved in developing two PACE sites that serve 850 individuals. The state received a Money Follows the Person award that includes older adults in its target population. Ohio does not have a state-funded home care program separate from the Medicaid waiver, but it does have a somewhat unique funding stream in which local communities use tax levies to support in-home services. In 2008, 70 of Ohio’s 88 counties had property or income tax levies that raised $140 million for home care services and served about 25,000 older people with severe disabilities.

To assess how these state policy changes affect long-term utilization in Ohio, we have tracked HCBS and nursing facility use since 1993. These data suggest a good news-bad news scenario for the state. The bad news is that, although the supply of nursing facility beds has remained constant, the state still has an excess of beds. Despite nursing home certificate of need reform, the state has no mechanism to remove excess beds from the system. The good news is that nursing homes voluntarily have removed about 7,000 beds from service, and, while Ohio has experienced an increase in the number of individuals age 85 and over by almost 75,000 in the last 15 years, occupancy rates have dropped from 91.9 percent to 87.7 percent (see Table 1). More bad news is that Ohio ranks 6th in the nation in the proportion of the population age 75 and older using nursing homes (AARP, 2009).

The effects of expanding HCBS are shown in Figure 1. Ohio has made significant inroads to change the distribution of long-term services and supports. In 1993, of all individuals age 60 and over receiving Medicaid long-term care services, 91 percent received services in a nursing home setting and 9 percent in the community. By 2009, the proportions had shifted such that 59 percent of individuals received services in nursing homes and 41 percent in the community. Because nursing home costs are higher than HCBS, the spending ratio is 72 percent nursing homes versus 28 percent community-based, resulting in Ohio remaining a state with relatively high institutional expenditures.

As states expand HCBS, policymakers often question whether such changes will increase pressure on the system by encouraging additional individuals to receive services in less restrictive settings. Because of the Medicaid cost pressure faced by almost all states, some policymakers have referred to this phenomenon pejoratively as the “woodwork” effect, suggesting that previously hidden consumers will surface from everywhere if a home care benefit is offered. Our analysis of longitudinal utilization data suggests otherwise. As shown in Figure 2, although Ohio has expanded HCBS considerably, the overall Medicaid utilization rate has remained relatively constant. In 1997, the utilization rate for Medicaid long-term services was 32 per 1000 persons age 60 and older. By 2007, despite the substantial increase in the number of older people using HCBS, the overall Medicaid utilization rate had grown just slightly to 34 per 1000 (Mehdizadeh, Applebaum, Deacon, & Straker, 2009). Thus, while Ohio has shifted the location of services, concerns about significant numbers of net new home care recipients did not materialize.

The data presented in this section indicate that Ohio made considerable progress with these incremental efforts. Despite these advances, the state in 2006 continued to rely heavily on nursing facility care. The large supply of nursing home beds and the
relatively high Medicaid reimbursement rates meant that despite the expansion of HCBS, the fundamental structure of long-term care remained problematic; incremental changes were not enough to alter dramatically the state’s approach. Nursing home care continued to be an entitlement and HCBS were funded by a waiver that restricted the number of individuals to be served.

Governor’s Unified Budget Long-Term Care Workgroup

In response to these structural challenges, the then newly elected governor appointed a workgroup to plan for the state to unify delivery and funding in the long-term services system. This represented the first time in state history that a group comprised of professionals, advocates, consumers, researchers, administrative staff, and legislators met to address the system design challenges. The workgroup identified five focus areas, and used subcommittees to develop a series of recommendations for the overall group. Subcommittee topics were: (1) analysis of the “front door” entry process into the long-term care system; (2) review of the need for and type of care management; (3) identification of opportunities to improve consumer direction; (4) improvements in the quality assurance and improvement aspects of the system; and (5) an administrative subcommittee charged with developing a mechanism to unify the long-term care budgeting process and information system, and performance outcomes of the newly developed system.

The workgroup met monthly for 18 months and, with the help of the subcommittees, generated a report that included 120 specific recommendations (Ohio Department of Aging, 2008). Although there were some minor disagreements, the major recommendations were supported widely by the workgroup. Most importantly, the workgroup recommended that the entire state long-term services budget be unified in one budgetary line. Thus, all Medicaid funds for long-term services and supports would be available for this purpose, regardless of the setting in which services are delivered. To implement such a plan, the workgroup recommended that the three Medicaid waiver programs for individuals age 60 and over be combined into one single waiver and that there would be no restrictions on where an individual could receive a Medicaid-funded service. Details on how the budget unification process would actually occur still need to be finalized.

Again, there is good news and bad news surrounding state long-term care reform. On the plus side, the recommendations are comprehensive and provide a sound blueprint for system reform. The governor recommended that the workgroup remain in existence, and he expanded membership to a broader array of stakeholders. Representatives of the legislature continue to participate in the workgroup. On the negative side, many of the proposed recommendations require legislative and administrative action for implementation. Unfortunately, state budget cuts caused the governor and the legislature, even though both were in support of the unified budget concept, to abandon the reform principles at the 11th hour of the budget process due to a perceived lack of funds. So, although the principles of a unified budget are supported widely, the state budget limited HCBS availability and kept nursing home care unrestricted. Between June 2009 and March 2010 the home care waiver program generated large

Table 1 Ohio Nursing Facility Admissions, Discharges, and Occupancy Rates: 1992-2007

<table>
<thead>
<tr>
<th>Year</th>
<th>1992</th>
<th>1993</th>
<th>1997</th>
<th>1999</th>
<th>2001</th>
<th>2003</th>
<th>2005</th>
<th>2007</th>
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<tr>
<td><strong>Nursing Facility Beds (in Service)</strong></td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Total beds</td>
<td>91,531</td>
<td>93,204</td>
<td>99,302</td>
<td>95,701</td>
<td>94,231</td>
<td>90,712</td>
<td>91,274</td>
<td>92,443</td>
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<td>82,207</td>
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<td>47,534</td>
<td>62,088</td>
<td>N/A</td>
<td>86,701</td>
<td>91,659</td>
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<tr>
<td><strong>Occupancy Rate (Percent)</strong></td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>91.9</td>
<td>90.7</td>
<td>87.7</td>
<td>83.5</td>
<td>83.2</td>
<td>84.7</td>
<td>86.4</td>
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waiting lists as a result of this policy. As of the first of March, the governor shifted funds to fund fully the home care waiver, so the waiting list soon will be eliminated. This example shows that, even with a supportive governor and legislature, difficult economic times can challenge reform efforts. Thus, despite a strong set of recommendations to address the long-term system challenges, the structural impediments to create a balanced system in the state persist.

**A Renewed Effort at Nursing Home Diversion and Transitions**

The final part of Ohio’s reform involves a renewed effort to divert people from entering nursing homes and to transition older people from the nursing homes back to communities. In response to arguments brought forth by home care proponents about Ohio’s overuse of nursing homes, the Ohio Legislature called for the Ohio Department of Aging to create a special program for diversion and transition. The legislative language was linked only to minor budgetary allocations, assuming that certain modifications to AAAs’ practices could result in improved diversion or transition outcomes. For example, placing AAA care managers in nursing facilities to assist an individual in returning to the community could lead to transitioning a person who otherwise would have remained in the nursing home.

The Ohio Department of Aging has formed a committee comprised of AAA staff, state program personnel, and researchers that faces several challenges in developing an intervention that could be tested and evaluated. First, the intervention needs to be delivered in a way that is significantly above and beyond the day-to-day home care efforts already provided to 30,000 older Ohioans through the current waiver programs. For example, individuals identified for this program must be at great risk for long-stay nursing home placement and must require additional assistance, such as high-risk case management or a substantially increased service plan. Second, because many individuals leave nursing homes each day on their own after short-term rehabilitative stays, it is critical that transition efforts are targeted accurately. For example, in a recent study of all Ohio nursing home admissions, we found that after three months, 43 percent of all admissions remained in the facility, and after six months 32 percent remained (Mehdizadeh, Applebaum, & Nelson, 2007). Finally, it is critical that AAA staff work with an array of service providers, including those specializing in programs for individuals under age 60, those with mental health needs, and those in need of supportive housing.

Over a six-month time period, the committee developed a range of diversion and transition strategies. The intervention strategies are divided into those designed for individuals currently enrolled in one of the Medicaid waiver programs and those currently not enrolled. The committee further divided the strategic efforts into four categories: (1) better mechanisms to identify at-risk consumers; (2) improved information to consumers and providers about home care options; (3) improvements in the care management interventions; and (4) the development of system-level change strategies, such as improved performance indicators.

Each of the 12 regional AAAs was able to tailor a range of interventions to their specific sites, some of which were adopted across the state. For example, all sites are reviewing their disenrollment rates to nursing homes and are identifying whether specific activities—such as increased service allocations or more intense care management—could reduce the proportion of those leaving sites to enter nursing homes. Other efforts like placing care managers on-site at specific hospitals and nursing homes to facilitate diversion and transition vary by region. Additional examples
of interventions that vary by region include sites attempting to work more extensively with the mental health sector, the housing and supportive services arena, and those organizations serving individuals under age 60. This specific intervention includes an evaluation that will follow individuals at four, eight, and 12 months after the diversion/transition strategy is implemented. The evaluation is designed to record the nature of the intervention and to link these activities to participant outcomes.

Can Big States Achieve Long-Term Service Reform?

The evidence from Ohio indicates that there has been progress on long-term care system reform. On a range of measures, Ohio indeed has moved forward in creating a more balanced system. On the other hand, Ohio still spends the majority of its Medicaid funds on institutional care and provides in-home services as a waiver; it views institutional care as an entitlement and lags behind the majority of states on the long-term care system balance indicators. Despite good political support, efforts to create a more balanced system continue to face major structural impediments. The costs and pressures associated with shifting expenditures during an economic recession are difficult, especially in light of the importance of the nursing home industry to local economies and its ongoing political strength at the legislative level.

Ohio’s experience demonstrates both the challenges faced by large states and the progress that is possible even in the face of these circumstances. The slow and steady progress of the state suggests that given enough lessons, elephants can learn to dance. Despite this progress, Ohio, like many other large states, is not yet ready for “Dancing with the Stars.”

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