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**Chapter 18**

**The Aging Network and the Future of Long-Term Care**

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**SUMMARY**. Federal and state governments face a significant challenge in meeting the long-term care needs of an older population that will double in size between 2000 and 2020 and continue to increase through 2050. States have made significant improvements in their long-term care systems for the elderly. However, they are still spending a significant proportion of their long-term care funds on nursing homes. Any effort to improve long-term care for the elderly quantitatively, and not just on the margins, must be focused on developing a more flexible and balanced long-term care system that is responsive to consumer choice.

The Aging Services Network is poised to play a significant role in this transformation process. The strengths of the Network include the ability to develop and manage consumer-driven community-based programs; to assess the needs and resources of individual older persons and provide cost-effective community supports; to operate within fixed, capped budgets; and to identify and maintain roles for informal caregivers. Now is the time for national aging organizations, state units on aging, and area
agencies on aging to use existing opportunities to move towards the establishment of a balanced system of long-term care. [Article copies available for a fee from The Haworth Document Delivery Service: 1-800-HAWORTH. E-mail address: <ddedelivery@haworthpress.com> Website: <http://www.HaworthPress.com> © 2003 by The Haworth Press, Inc. All rights reserved.]

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INTRODUCTION

We have heard a lot of talk about the aging of the baby boomers for the last 10 to 15 years. Much of this talk is about the challenge to federal and state governments and families to meet the long-term care needs of an older population that will double in size between 2000 and 2020 and continue to increase through 2050. Perspectives regarding the progress made thus far by states, local communities and the nation as a whole differ widely. This debate will continue as the aging baby boom increases the demand for long-term care services and specifically for home and community-based service options.

Most states have made significant improvements in their long-term care systems for the elderly. States have used a variety of approaches to increase the amount of home- and community-based service options that they provide to older adults and their family caregivers. One significant mechanism utilized by states is the Medicaid waiver that allows for the funding of home- and community-based services as alternatives to Medicaid-funded nursing home care. However, 75 percent of public funds for long-term care still goes to nursing homes. This proportion has decreased only slightly from the percentage that was spent 10 to 15 years ago.

The U.S. long-term care system for the elderly is largely characterized by a loosely organized and fragmented process of gaining access to care and a bias favoring institutional care for publicly supported long-term care consumers. This bias makes it difficult for states to provide easy and timely access to home and community-based service options. Any effort to improve long-term care for the elderly qualitatively, and not just on the margins, must be focused on developing a more flexible and balanced long-term care system that is responsive to consumer choice.

Our goal should be to make our long-term care system more responsive to the needs and preferences of older people and their families by empowering older people and their families to make informed decisions about their life choices, and creating more flexible service options from which people can choose. Choices that will:

- Help people maintain and improve their health as they age,
- Help families care for their loved ones, and, most importantly,
- Help older people stay at home.

Three factors exist that together provide an impetus for a qualitative transformation of long-term care for the elderly.

(1) An extensive community-based aging network. This network includes 56 state units on aging, 655 area agencies on aging, thousands of non-profit, in-home and community-residential service providers and monitoring and advocacy groups like the nursing home ombudsmen. The aging network is over 30 years old and has the capacity in many communities to provide a full range of consumer-oriented home- and community-based long-term care services. A majority of the states have recognized this capacity by giving the aging network, at both the state and service delivery levels, responsibility for administering all or most of the aging-related home- and community-based Medicaid waiver funds.

The aging network in most parts of the country has more experience and expertise in non-medical care management than any other organization. According to one state unit on aging, “this experience has been focused particularly on creating and packaging a wide range of relatively low-cost home and community-based services to minimize frail older persons’ use of high-cost institutional resources” (Managed Care Approaches to Long-Term and Integrated Care, New York Office for the Aging, 2002).

(2) The cost-effectiveness of long-term care services (HCBS). The cost-effectiveness of HCBS has been demonstrated through research conducted over the last ten years and by the success of a few states in qualitatively shifting the balance of their long-term care system from institutional to community-based care. These efforts have included the implementation of innovative programs such as consumer-directed care and Medicaid waiver-funded assisted living and foster home programs. This research is complemented by the fact that older people vastly prefer community-based alternatives to nursing homes.

In their study of Oregon, Washington and Colorado’s successful efforts to contain long-term care costs by expanding home- and community-based services, Alexxih, Lutzky, and Corea (1996) conclude that these states:
they can create a more balanced long-term care system that better serves the interests of the long-term care consumer. In many states, the management of long-term care programs is split between departments of aging/senior services (home- and community-based programs) and departments housing the Medicaid program (nursing homes and so on home care). Only a few states have consolidated control over long-term care programs and funds into one agency. Accountability of long-term care program outcomes would be substantially enhanced by integrating authority and responsibility into a single organization structure. Accountability for outcomes and administrative efficiency will become an increasingly urgent issue for policymakers at all levels as the need for long-term care services grows over the next seven years. As trade-offs become necessary, both efficiency and consumer choice will be better served if decision-making is integrated within organizational structure with authority over all long-term care resources.

An alternative method of balancing the distribution of long-term care resources is to develop a program at the local or regional level that manages multiple long-term care program funds and operates under a fixed rate. The fixed rate could be constructed through negotiation between representatives of the aging network, under the leadership of the state's aging unit, and the state's Medicaid office, and incorporated into a contract. Wisconsin has taken this approach with the Wisconsin Family Care Program, and Arizona has operated this type of a system statewide for several years (Weissert, Lesnick, Musliner, & Foley, 1997).

The Wisconsin Family Care Program has two components—aged and disability resource centers and care management organizations. The resource centers serve as single points of entry into the long-term care system, providing information and counseling on all long-term care, preventive healthcare, and early intervention services. An important feature of the Resource Centers is their long-range goal to serve only Medicaid-eligible consumers, but also private-pay consumers and their families. Providing information and assistance to the non-Medicaid population is an important element of any strategy to change long-term care systems. About 10% of the elderly are Medicaid-eligible and many of these people become Medicaid-eligible after they "spend-down" their own resources on health care and other costs associated with chronic conditions, including nursing home care. A program that assists private-pay consumers holds great potential for empowering all older people to make informed decisions about their care choices. In addition to having access to help from the Resource Centers, those on

**IMPROVING ACCESS AND BALANCING LONG-TERM CARE RESOURCES**

States may need to make changes in their organizational and administrative structures and the ways they control the use of resources before...
private-pay plans will eventually be able to purchase Family Care home- and community-based services through payments based on a sliding scale fee.

In building aging network-based care systems, area agencies on aging and community-based providers are uniquely prepared to play roles which capitalize on both their understanding of older persons and their experience in delivering home- and community-based services. Their strengths include the ability to develop and manage community-based programs; to assess the needs of individual older persons, identify appropriate services and provide cost-effective community supports; to operate within fixed, capped budgets; and to identify and maintain roles for informal caregivers. Now is the time for national aging organizations, state units on aging, area agencies on aging, and community-based providers to use opportunities such as gradually expanded demonstration projects to move towards the establishment of balanced systems of long-term care.

**IMPROVING LONG-TERM CARE IN RURAL COMMUNITIES**

The need to balance the distribution of our scarce long-term care resources is especially evident in our rural communities. It is more difficult to provide home- and community-based care in rural environments because of transportation expenses, acute labor market shortages and other “economies of scale” limitations that drive up the costs of serving persons in their own homes or smaller congregate care settings. As a result, rural communities are often more dependent on nursing homes than urban areas.

Aging network-based efforts to coordinate the distribution of long-term care resources across large geographical areas could achieve the “economies of scale” required to provide more community-based services to rural residents. Programs could be redesigned to centralize a number of management functions, including client information systems, financial and personal management, public information services, and administration functions. These efficiency initiatives could generate more resources for services and promote a consumer-centered delivery of care. The additional resources could be used to fund the expansion of consumer-directed care, adult foster homes, and other small congregate providers, including small assisted living facilities (15 beds or fewer), which may be more cost-effective than conventional agency-provided in-home services (personal care, homemaker, respite) in rural environments.

Section V. Looking Ahead: Training and Policy Recommendation

**OVERCOMING BARRIERS TO HOME- AND COMMUNITY-BASED CARE**

A recent analysis by Wiener, Tilly, and ALEXH (2002) of long-term care systems in seven states identified several major questions that federal and state governments need to answer as they attempt to balance the distribution of long-term care resources.

1. Can states achieve significant progress in the development of home- and community-based service options in the midst of a significant financial crisis?
2. Can states overcome administrative fragmentation to create more integrated, uniform method (single entry point) of providing access to services?
3. Will states provide a broader and more flexible set of service the future? How will states address the increasing frailty and medical complexity of their clients?
4. Will states be able to contain costs while expanding services?
5. Can quality of home- and community-based services be assured?

Government at every level is facing the challenge of providing affordable and cost-effective long-term care options for older adults in order to meet existing and future needs. The current economic climate makes it even more important to provide these cost-effective options to nursing home care. By doing so, states will also achieve greater balance in the distribution of long-term care resources.

A potential method for expanding community-based long-term care is to create linkages with the community of faith-based organizations many of which have long provided a wide range of assistance to the elderly. This history, along with the fact that the elderly are a growing percentage of many congregations, could serve as the foundation for major expansion of long-term care services by faith-based organizations over the next several years. The aging network and faith-based organizations are both driven by a sense of mission defined by an ethos. This potential alliance, which has already emerged in some communities across the country, would be supported by efforts of the national network to balance the use of long-term care resources.

Regardless of the method utilized, the needs, preferences, and capacities of consumers must ultimately determine how long-term care services are used and to determine the most appropriate use of available services. This is especially true in our attempts to provide home-
community-based services to increasingly frail consumers with complex medical needs. Many states are testing innovative models to coordinate this care in a consumer-oriented and efficient manner. Such programs include the Program for All-Inclusive Care of the Elderly (PACE), Social Health Maintenance Organizations (SHMO), and the Medicare/Medicaid Integration Projects. Virtually everyone involved in long-term care policy and practice supports the goal of a comprehensive and coordinated continuum of care delivered through a seamless system of acute, chronic, and long-term care services. Such a system is some distance in the future, but the aging network can begin to put the building blocks in place now.

IMPLICATIONS FOR SOCIAL WORK

Achieving a balanced long-term care system will depend on a substantial extent on the increased availability of social workers trained to assist the frail elderly to access service options in a way that maintains the consumer’s role as central to the process. Social work education should be designed to prepare long-term care case managers to empower consumers through collaborative need and strength assessments and care planning processes that prioritize the preferences of the consumer and maximize the consumer’s capacity to direct where, when, and by whom services are provided.

We do not know precisely what percentage of long-term care consumers have the desire and capacity to exercise extensive control over the provision of services, including the power to hire and manage personal care workers. The point, however, is to prepare case managers to help consumers understand all of their options in a community-based system of care, including consumer-direction, and to provide them with the kind of support most consistent with their preferences and capacities. Case managers will still need to monitor the quality of care and to intervene when abuse or fraud occur. But, as advocates for consumer empowerment, they must be willing to accept the risk that comes with greater consumer choice and responsibility and the possibility that their notion of sufficient, high-quality care may not be the same as the consumer’s.

A key component of the critical role for social workers is to link directly with doctors and nurses in the delivery of care management. An interdisciplinary team approach has been found to be the most effective means to manage the multiple chronic conditions that may be present in an older adult. Care management delivered through such a team ensures that the social support needs—not just the healthcare needs—of the older adult are met. It is equally important for the interdisciplinary team work closely with an older adult’s informal support network in order to help them maintain the highest quality of life and level of independe possible.

CONCLUSION

Changing the direction of long-term care will be very difficult will require, in most states, a major effort in every year remaining between now and 2020. The task, however, of creating a more consumer-oriented community-based long-term care system will not be difficult, either politically or fiscally, as trying to maintain the current system for another 20 years. We should marshal the resources of the aging network to modernize long-term care and to take advantage of opportunities created by the Supreme Court’s Olmstead decision, President’s New Freedom Initiative, and the CMS Real Choice System Change grants program. It is time for the aging network to provide kind of leadership that can create a coalition of all affected parties by articulating a clear vision for reform based on the needs and preferences of long-term care consumers.

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