Home- and Community-Based Long-Term Care: Lessons From Denmark

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Purpose: Denmark is cited as a model in the development of home- and community-based systems for the frail elderly population. We examined the results of this natural experiment and considered implications for U.S. policy. Design and Methods: We used international comparative policy analysis, including site visits and semi-structured interviews with Danish leadership in conjunction with a review of published literature, reports, and administrative data from Denmark and the United States. Results: After 12 years of implementing integrated systems for home- and community-based services in 275 municipalities, growth in Danish long-term care expenditures has leveled off; expenditures appear to be decreasing for the over-80 population and have dropped as a percentage of the gross domestic product. Access to and quality of long-term care services appear to remain generally satisfactory. During this period, comparable expenditures in the United States have increased, and deficits in access and quality persist. Implications: These findings should be of interest to state and federal policy makers considering strategies to reduce the rate of growth in Medicaid and Medicare expenditures for elders and to expand home- and community-based services.

Key Words: Long-term care, Medicaid, Medicare

Despite considerable attention, the United States’ ability to meet the long-term care needs of its aging population remains an issue of pressing national concern. Projections for the future, ranging from two to four times the current number of disabled elders by the middle of the century (Friedland & Summer, 1999), have sparked debate regarding the magnitude of projected costs. Controversy also enshrubs the question of whether economic growth will be adequate to finance future costs and how to construct policies that maximize participation of elderly people in the labor force. However, no one argues that our current long-term care system is well suited to meet the needs of today’s elders, let alone to address tomorrow’s needs. Testifying before the U.S. Senate’s Special Committee on Aging (Scanlon, 1998), a senior official reported, “What we know today with some certainty is that the aging of the baby boomers will lead to a tremendous increase in the elderly population in the next 3 decades, with an even larger increase in individuals aged 85 and over, who are more likely to use long-term care services. What is less certain, however, is the nature, magnitude, and funding sources for those services. Financing these services—within the context of evolving service needs and alternatives—will be a challenge for the baby boomers, their families, and federal and state governments” (p. 2–3).

Denmark has been widely recognized as a leader in care for its elderly population and is often cited as a model by European experts. In the context of considering policy alternatives for the United States, it may be useful to examine the results of the Danish expansion of home- and community-based services (HCBS). To better understand the history and structure of these Danish systems, we conducted a series of site visits and semistructured interviews with senior public health officials, providers, and economists in Denmark between 1995 and 1999. To determine outcomes for Danish HCBS, we reviewed published literature, program reports, and administrative data.

Overview of the Danish System

In the early 1980s Denmark began to face demographic trends not unlike those facing the United States today—increasing numbers of elderly people and a declining work force. At the time, Denmark relied heavily on an institutional system of care. By the mid 1990s there were extensive systems of HCBS available throughout the country; just under 29% of the elderly population were receiving some form of long-term care, and approximately 25% (one in four) of persons aged 67 and over were receiving home help (Danish Ministry of Finance, 2000).

The Danish system is based on a structure that
Denmark's Expansion of Home Care

In the early 1980s, in response to policy direction from the national government, local municipalities began to experiment with 24-hour home care services as an alternative to nursing homes. Services included home help (e.g., assistance with domestic tasks such as housecleaning) as well as nursing care. After-hours service for acute needs was provided in addition to regularly scheduled visits. By the mid-1980s, municipalities began to experiment with new forms of housing for disabled elders, emphasizing the development of various types of assisted living in lieu of new nursing home construction. In 1988, legislation was passed limiting the construction of new nursing homes (Pederson, 1998), and remaining nursing homes were converted to single-occupancy rooms (personal communication, L. Wagner, April 4, 2000). Care was taken to minimize perverse financial incentives for institutionalization; individuals pay for housing and the government pays for necessary health and social services, regardless of the setting in which care is received (Hansen, 2000). In 1997 another law mandated that all new housing for elders must have at least the following rooms: bedroom, sitting room, kitchen, and bath (personal communication, L. Wagner, April 4, 2000).

The mid-1990s also saw widespread adoption of an approach referred to by the Danish as "the integrated care system." Where earlier, nursing homes and home care organizations were staffed separately, with the integrated care system only one organization cares for elderly and disabled people in a district (Hansen, 2000). This organization provides the necessary services regardless of the type of housing. The integrated care system, which is now in use in approximately 75% of municipalities, was developed originally under the direction of Lis Wagner, RN, in Skaevinge, a small rural community north of Copenhagen (Wagner, 1997).

Skaevinge was one of the earliest and most successful of the Danish demonstration projects. Beginning in 1984, Skaevinge took what was, at the time, a radical approach. After an intensive planning process, this community decided to eliminate its one existing nursing home. The facility became a hub for community support services that include a senior center, day care, rehabilitation, 24-hour home care, and assisted living. Nursing home staff were guaranteed jobs in the new plan. During the transition process from nursing home to community care, staff had to learn to avoid taking over responsibility for tasks residents could do for themselves, and residents had to relearn self-care skills. The community was divided into three geographic service areas and staff were divided into three teams, each assigned to serve the residents of a given geographic area.

Today, geographic integration of services facilitates transitions in the continuum of care. When an individual in Skaevinge becomes ill and requires closer supervision than can be provided in the home, she comes into the assisted living unit until well enough to go home. Similarly, someone who has been hospitalized may be discharged to the assisted living facility until able to go home. At night, a skeleton staff provides coverage for all three service areas. The staff believe that even severely demented residents function better in the company of less impaired individuals, so these residents live among others in the assisted living facility, although with special therapeutic services devoted to them (Wagner, 1994; site visit and interview with L. Wagner and P. Poulsen, Skaevinge, Denmark, May 4, 1999).
Odense, known to Americans largely as the home of Hans Christian Andersen, is another of the communities that the Danes consider a model for HCBS. Odense, like Skaevinge, has eliminated its nursing homes. However, where Skaevinge converted the existing nursing home into an assisted living unit operated by the municipality, Odense entered into a partnership whereby private developers build and operate new assisted living units with the municipality providing the health and social support services. The assisted living facility in Odense provides a hub for community services including day care, rehabilitation, and 24-hour home care. As in Skaevinge, we observed demented patients living and eating next to the nondemented residents (Elderly Policy, 1995; site visit to Odense, June 1995).

**Outcomes**

How successful have the Danes been in increasing access to HCBC? What has been the impact on costs and quality of care? As measures of access we consider increases in adaptive special dwellings (a new type of housing introduced in 1988 to replace nursing homes and older forms of municipal housing, consisting of apartments specifically adapted for the needs of older people), utilization of home help, and reductions in nursing home beds. As measures of quality, we consider consumer satisfaction. To assess the relative growth in expenditures between Denmark and the United States we compare total expenditures (i.e., both public and private expenditures) for nursing homes and home health care between 1985 and 1997. To determine whether change has occurred in the amount each nation is spending on such care in relation to the size of the economy, we compare total expenditures as a percentage of GDP in 1985 and 1997. Finally, to determine whether differences in total long-term care spending might be explained by differences in the number of elderly individuals or the proportion of the population that has become “old elderly” (i.e., those with the highest use rates for long-term care), we calculate a ratio using total expenditures as the numerator with the number of people aged 65+ and 80+ as the denominator.

In some instances we compare Danish outcomes and cost with those reported in U.S. studies to provide a context for the reader. Such comparisons must be viewed with caution. Outcomes and costs are best evaluated within a culture and service delivery system (Perrin, Durch, & Skillman, 1999). Comparisons between the United States and other nations are fraught with difficulties. Not only do patterns of illness vary, even between different states in the United States, but the structure of medical and social service systems differs as well. Thus, comparisons are based on available, rather than strictly comparable, data.

**Access**

Between 1985 and 1997, the number of nursing home beds in Denmark decreased 30% (Hansen, 2000), whereas nursing home beds in the United States increased 12% (National Center for Health Statistics, 2000). As shown in Table 1, the number of individuals older than age 65 in Denmark remained stable at 15% during this period, whereas the proportion in the United States rose from 11.9% to 12.8%. In Denmark, the number of beds per thousand people aged 65 and over decreased 32% compared to a 7% decrease in the United States. The proportion of very old (80+) individuals increased in both countries by about 25%. Thus, although Denmark started with a larger percentage of elderly people, the growth of the very old, in those most likely to require long-term care, has been comparable. In Denmark, the number of beds per thousand people aged 80 and older decreased 45%, compared to a 21% decrease in the United States.

The decrease in Danish nursing home beds was accompanied by an increase in adapted dwellings for elders and in the use of home help. Between 1985 and 1998 the number of sheltered housing and other adapted dwellings in Denmark increased 331%,

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<th>Table 1. Change in Nursing Home Beds and Long-Term Care Expenditures in Denmark and the United States</th>
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*Expenditures adjusted to 1997 prices by consumer price index.  
Sources: Calculations based upon gross domestic product (GDP) for Denmark and the United States (International Monetary Fund, 2000); population (U.S. Bureau of Census, 2000); U.S. nursing home beds (National Center for Health Statistics, 2000); and U.S. long-term care expenditures (NHE). Danish nursing home beds and expenditures calculated by E. B. Hansen based on Statistics Denmark, 1989 and 1998.
Quality of Services

As Denmark reduced access to nursing homes, the major concern was whether new housing modalities and home care services could keep pace with the needs of an increasing number of disabled elders. Evaluations from some of the earliest experiments with 24-hour home care indicate that these services increased older people’s sense of security (Hansen & Werborg, 1984). A study conducted at the end of the 1980s (Pederssen, 1992) reported that a marked shift in attitude had occurred in attitudes toward aging, with people showing “an optimistic and self-confident attitude to their own old age.” More recent evaluation studies do not indicate a decline in overall consumer satisfaction with long-term care services available to elders (Pederson, 1998), and users generally feel they receive enough help with personal care and home nursing (Hansen & Platz, 1995).

Despite this generally positive assessment, there is widespread recognition that the quality of long-term care varies among the municipalities. In areas where the level of home help has been reduced, a significant number of residents express dissatisfaction with the amount of help available for domestic tasks such as housecleaning (Hansen & Platz, 1995). As opposed to other European countries, individuals receiving permanent home help pay no user fees, and this benefit is not means tested (Danish Ministry of Finance, 2000). Nonetheless, efforts to introduce private payment for practical home help services have been controversial. Daneage, an advocacy group for the elderly population, takes credit for helping block such a policy change in 1999. It successfully took three cases to court where a municipality had cut back on practical home help services for a disabled elderly individual; also, it advocates increasing the availability of nursing homes for elders who might prefer this mode of care (Daneage, 2000). In response to widespread criticism of the amount and quality of home help given to elderly people, the right to appeal has been enhanced. Since 1996, municipalities have been required to explicitly define the service package available locally, develop service specifications, and set up local boards to hear complaints (Pederson, 1998).

Danish experts indicate that the municipality of Skaevinge continues to serve as a model, citing a recent evaluation of the Skaevinge project from its inception in 1984 to 1997. This study reports high levels of satisfaction among residents and staff, improvements in both self-reported and actual health status, and reductions in hospitalizations, particularly among the “old elderly.” The proportion of individuals rating their health as better than average (when compared to their peers) rose from 29% in 1985 to 41% in 1997. This improvement in self-rated health scores is mirrored by a statistically significant decline in the number of elders with diagnosed circulatory disorders. The proportions of older people reporting dependence in ADLs (walking, toileting, dressing) remain unchanged although there is an improvement in the proportion who report that they can cut their own nails, pick up shoes from the floor, prepare their own food, and do their own laundry (Knudsen, Christensen, Friis, & Wagner, 1999). In summary, the picture from this study is one of an elderly population whose health status has improved somewhat and whose physical capacities are largely unchanged from those of an earlier cohort, but who appear more satisfied with their health and are more confident of their abilities. Given the many factors that can affect health status, these improvements cannot be attributed solely to the provision of HCBS. Nonetheless, the shift from nursing homes to HCBS cannot be said to have undermined the health status of elders in Skaevinge.
Costs of HCBS

What has been the impact of the Danish shift toward HCBS on total long-term care spending? Between 1985 and 1995, total long-term care expenditures as a percentage of GDP dropped from 2.4% to 2.2% of GDP for the Danes (an 8% decline), whereas in the United States total long-term care expenditures as a percentage of GDP increased from 1.03% to 1.59% (a 54% increase). Note that although the proportion of elders in the U.S. population increased as opposed to Denmark, where it remained stable, the increase of less than 8% in the proportion of elders cannot account for the magnitude of the expenditure increase.

During this same period the ratio of total expenditures to the population aged 65+ increased 8% for the Danes, whereas in the United States the ratio of total expenditures to population 65+ increased 67% (see Table 1). The percentage change in spending is most striking in reference to the population aged 80+, the segment of the population that is most at risk for nursing home care. Between 1985 and 1997, Denmark achieved a 12% reduction in the proportion of long-term care expenditures to the population aged 80+. By contrast, the United States realized a 68% increase. In 1985 the ratio of Denmark’s long-term care expenditures to the population aged 80+ was nearly twice that of the United States ($16,811 for Denmark compared to $8,949 for the U.S.). However, by 1997 this ratio was similar for both countries ($14,818 for Denmark compared to $15,008 for the U.S.).

Careful consideration to the comparability of the expenditures between the two countries is warranted. Whenever an accounting construct is designed, it is important to understand what is measured, the data sources, and methods used (National Health, 2000). All expenditures have been adjusted to 1997 dollars to control for inflation. Our estimates for both countries include durable medical supplies and equipment and nursing home expenditures for the nonelderly disabled as well as the elderly populations. We have excluded from U.S. long-term care estimates Medicare expenditures for hospital-based skilled nursing facilities, because these facilities largely provide care relating to acute illness, and comparable patients in Denmark would remain in the hospital. The value of time spent on caring by informal caregivers is excluded from both the Danish and U.S. expenditures.

Danish figures for home care exclude the estimated costs for services to nonelderly disabled individuals. Consequently, we have excluded Medicaid payments for personal care and for home- and community-based waiver services from our calculations. Although in a few states these programs are a significant source of home care for elders, we chose to omit them from our comparison because available U.S. data for 1997 do not differentiate Medicaid expenditures by age for these services. If we adjust U.S. 1997 data proportionately, using data from 1995 (Wiener & Stevenson, 1998), long-term care expenditures for the United States would increase by about 1%.

U.S. home health care expenditures are from the U.S. National Health Expenditure Accounts (NHE), which define home health care services (National Health, 2000b) as “medical services delivered in the home by private and public nonfacility-based home health agencies.” The NHE include Medicare, Medicaid, and private expenditures with certain exceptions. Medicare hospital-based home health expenditures are not included, nor are other public expenditures for home care that are channeled through programs that do not have the provision of care or treatment of disease as their primary focus. Thus, expenditures for nonmedical home care services such as housecleaning, meals on wheels, chore-worker services, or other custodial services for disabled elders that are publicly funded through Title XX of the Social Security Act, the Older Americans Act (Administration on Aging, 2000), or with state, county, or local appropriations are excluded from U.S. estimates; however, comparable services would be included in the Danish estimates. These expenditures are relatively small and, if included, would increase estimates of U.S. total long-term care expenditures by about 3%.

Discussion and Implications for the United States

It appears that Denmark’s relatively small size, historic commitment to elder care, and political decentralization have provided a natural experiment in the development of efficient and “consumer friendly” HCBS for the elderly population. These findings can have important implications for the United States, where fragmentation of financing makes evaluation of HCBS problematic. As a recent report from the ASPE Office of Disability, Aging and Long-Term Care Policy (Doty, 2000) noted, “It is difficult—indeed it is virtually impossible—to design and conduct research that truly measures cost-effectiveness as distinct from cost-shifting from one program to another, from state to Federal funds, and from formal to informal care” (p. 11). A number of states have implemented HCBS (see Leutz, 1999, for a review), and there is evidence that some of these may have produced savings (Alexich, Lutzky, & Corea 1996; Bodenheimer, 1999; U.S. General Accounting Office, 1994; Weissert, Lesnick, Musliner, & Foley, 1997). A few states have begun to emphasize construction of alternative residential facilities in place of nursing homes (U.S. General Accounting Office, 1994). However, because of the fragmentation in reimbursement, eligibility, and services for long-term care in the United States (Boult & Pascala, 1999), American elders do not receive the security afforded by the Danish system. As Feder (1999) aptly sums up the U.S. situation, “In long-term care, there is no ‘system’; almost nobody has protection” (p. 4).

Between 1985 and 1997, total expenditures for home care in the United States rose 470%, from $5.6 billion to $32.3 billion. Public expenditures for home care
care provided by Medicare and Medicaid grew 611%, from $2.5 billion to $17.7 billion (NHE, 2000). Despite the enormous growth in U.S. home care expenditures, many disabled elders lack the services they need. In contrast to the relatively positive assessment of Danish personal care and home health services, a recent study reports that nearly half of home care clients in the United States receive only some or none of the support services they need. Necessary services are not provided for several reasons: because they are not reimbursable; the demand for services exceeds supply; physicians who write the home care orders are unaware of all the patient’s needs; or the hospital discharge planners have not arranged for the proper mix of services (Thomas & Payne, 1998).

One frequently cited reason for not making home care more accessible in the United States is the “woodwork effect,” that is, the argument that if home care is offered as an alternative to nursing homes, more people will demand care and “community-based services are unlikely to save money, because the demand for these services will drown any unit cost savings” (Kane, Kane, Ladd, & Veazie, 1998, p. 364). The Danish experience is particularly interesting in this context because it would appear to represent a “worst case scenario” with regard to the woodwork effect. Among European countries, Denmark is noted for the independence of its elders—only 3% of those over age 70 live with their children (Kahler, 1992). Although studies have found that up to 60% of Danish older people receive some form of help from relatives, friends, and neighbors, this is rarely the sole source of care (Hansen & Platz, 1995). In Denmark, private expenditures for long-term care are very modest. Few people hire private assistance for home care, as these services are supplied without user payment. User copayments in nursing homes are also low, about 2.5% of total income for these institutions in 1997 (E. B. Hansen, personal communication, April 6, 2000).

By contrast, in the United States, 46% of home health care and 38% of nursing home care are paid for out of private funds (NHE, 2000). Approximately one third of people discharged from nursing homes pay with private funds when admitted but eventually spend down to Medicaid eligibility (Wiener, Sullivan, & Skaggs, 1996). Among elders with functional limitations who live in the community, 90% receive some informal care and 65% depend solely on help from family and friends (Scanlon, 1998). This help is often provided at considerable personal and financial cost to the caregiver as well as to the employer. One recent study (Schulz & Beach, 1999) found that participants who were providing care and experiencing caregiver strain had mortality risks that were 63% higher than noncaregiving controls. The value of time devoted to informal caregiving in 1997 was estimated at $196 billion (Arno, Levine, & Memmott, 1999).

Time devoted to caring for parents substantially reduces the labor supply for both men and women (Johnson & Lo Sasso, 2000). This factor was noted as a consideration in the Danish policy shift toward HCBS by several of the Danish experts we interviewed, and it has substantial implications for the United States as well. As declining mortality rates increase the number of older people, especially the “old elderly,” it is anticipated that declining fertility rates will reduce the number of children who will be available to care for their aging parents. At the same time, women at midlife, who have traditionally been the primary caregivers for frail elders, are participating in the labor force in increasing numbers (Friedland & Summer, 1999; Johnson & Lo Sasso, 2000). Unless efficient services for HCBS can be developed in the United States, these trends will create enormous pressure on future financing of long-term care as increased demand for institutional long-term care results in concomitant increases in expenditures (Friedland & Summer, 1999).

Conclusion

In 1985, Denmark was spending considerably more per capita on long-term care than was the United States. However, by 1997 Danish and U.S. per capita expenditures for the elderly population appear to be roughly comparable. U.S. growth in long-term care expenditures during the past 15 years has occurred despite the fact that cost containment has been a major priority for state governments, as it continues to be today (Wiener & Stevenson, 1998). Currently, there is reason for concern that Medicare cutbacks in home health care will further fuel increases in state Medicaid costs (Kenney, Rajan, & Soscia, 1998). In this context, the results of the Danish experience—that growth in expenditures has leveled off, expenditures have dropped as a percentage of GDP, and expenses appear to be decreasing for the over-80 population—are especially noteworthy for state leadership. Rather than discouraging further experimentation with HCBS and alternative residential housing for elders, the Danish experience suggests that these approaches can be successful in controlling costs for long-term care as well as increasing security for older people and their families. This experience may give some comfort to state policy makers as they grapple with the expansion of Medicaid HCBS mandated by the decision in Olmstead v. L.C. (Supreme Court of the United States, 1999).

We do not suggest that the Danish model for HCBS can or should be transplanted directly into the United States. Although Denmark’s development of comprehensive services to elders is impressive (without the impediment of the fractured funding and cost-shifting that so marks the U.S. health care system), the variation in services offered by Danish municipalities mirrors some of the variations in our own state Medicaid programs. Concerns expressed over attempts to cut back on housekeeping services to Danish elders, or to privatize these services, may seem trivial when contrasted with the problems U.S. elders have in obtaining home nursing and personal care.
care; however, it should be kept in mind that the “welfare state” ideology and egalitarian income structure in Denmark leave many elders with little discretionary income. In short, the issue of preserving individual freedom and autonomy for older people while optimizing resource allocation remains a difficult challenge for the United States and Denmark alike. It is in this context that we suggest that the Danish experience belies the common belief in U.S. health policy circles that HCBS cannot be cost-effective. In addition, municipalities such as Skævinge offer models not only in how services in an efficient system might be structured, but in how the transition process from institutional to community-based care can be successfully managed. We hope that consideration of the Danish experience will encourage and inform the efforts of U.S. policy makers to develop new and better systems of care for older Americans, even as they struggle with the ongoing need to contain costs.

References