Long-Term Care and Federal Policy

Frederick P. Somers

Key Words: aged • long term care • public policy

A major deficiency of national health care policy is the lack of a structured and comprehensive system of long-term care. A review of existing federal programs reveals that substantial resources are being expended to care for the elderly. Program structures and requirements, however, are frequently skewed toward institutional care to the exclusion of more appropriate home- and community-based services. A recent federal study highlighted the dimensions of the long-term-care problem and proposed a compelling remedy, but a consensus continues to elude policymakers, and the prospects for fundamental reform are uncertain.

The single most significant threat to the security of elderly Americans and their families today is the cost associated with long-term care. It is often not until chronic illness occurs that most older Americans discover that the range of services they need is not furnished by existing public programs or covered by private insurance. Federal policymakers have been aware for some time of the need to develop a national long-term-care policy. The confluence of several trends, however—notably, a rapid growth in the elderly population, the burgeoning costs of nursing home and other care, and an evolution of the family structure in our society—have combined with other issues to propel long-term care to the forefront of the health policy debate. Most recently, the report of the U.S. Bipartisan Commission on Comprehensive Health Care (1990), also known as the Pepper Commission, has renewed discussion on this compelling problem.

The lack of a rational, coherent system of long-term care also impedes optimal access to occupational therapy services, an important component in the continuum of care necessary for the maximization of functional capacity, independence, and quality of life for the elderly. Occupational therapy services, when available under existing federal and state programs, are frequently limited by statute or regulation in their scope, duration, or provision setting. These barriers, often perplexing and illogical, frustrate the potential of occupational therapy in enhancing the lives of those needing long-term-care services. In this article, I sought to examine some of the trends that are driving the long-term-care debate, the deficiencies in existing federal policy, and the prospects for reform.

The Long-Term-Care Population

Estimates of the long-term-care population, that is, the number of Americans of all ages in need of long-term-care services, are imprecise, primarily because of a lack of reliable data on the number of people in the noninstitutionalized population who currently receive only informal care. Estimates also vary depending on the standard used to assess degree of disability. Recent studies measuring assistance required with one or more activities of daily living or instrumental activities of daily living have suggested that approximately 11 million people spanning all age groups are dependent on assistance from others to meet these basic needs (U.S. Bipartisan Commission on Comprehensive Health Care, 1990).

Elderly persons living in the community or in nursing facilities constitute two thirds of the long-term-care population (U.S. Bipartisan Commission on Comprehensive
The American Journal of Occupational Therapy

Demographic Trends

Shifts in demographic trends are among the principal forces driving the increased demand for long-term-care services. At the beginning of the 20th century, life expectancy in the United States was approximately 50 years. Today, life expectancy averages 75 years. A man who survives to 65 years of age can expect to live another 15 years; a woman, another 19 years. Millions of Americans can now expect to live beyond the age of 85 years and, in many instances, well beyond that age (O'Shaughnessy & Price, 1988).

Due to advances in health care and social policies that have facilitated access to care, the number of elderly persons has been growing at a much faster rate than the number of persons under the age of 65 years. Forty years ago, those over age 65 years constituted 8% of the population. In 1990, there were approximately 32 million elderly in the United States, accounting for approximately 13% of the population. Projections indicate a doubling of that 32 million by the year 2030, even assuming a reduction in the rate of improvement in longevity. The number of oldest old, that is, those aged 85 years or older, could increase fivefold in the same time frame. If disability rates remain static, the number of elderly requiring long-term care could rise to 13.8 million, with almost 40% of those requiring nursing home care (U.S. Bipartisan Commission on Comprehensive Health Care, 1990). These trends in the elderly population combined with the potential for similar growth in the long-term-care population under 65 years of age lend further urgency to the need for a comprehensive national strategy for long-term care. These trends offer a compelling rationale for even greater participation by the occupational therapy profession in addressing such needs, ranging from the development and promotion of model occupational therapy programs in long-term care to the fostering of broader leadership and advocacy skills to facilitate participation in public policy development at all levels.

Long-Term-Care Spending and Services

Total national spending for formal long-term-care services from both private and public sources for institutional and noninstitutional care was approximately $53 billion in 1988. Of that amount, approximately $43 billion (80%) was for nursing home care. Less than 20% was devoted to home health care services (U.S. Bipartisan Commission on Comprehensive Health Care, 1990) (see Table 1).

Federal and state programs combined cover just over half of the total costs. The largest single source of government support is Medicaid, the federal-state entitlement program that pays for medical services for eligible low-income persons. Medicaid accounts for 90% of all public spending for nursing home care and more than 60% of the public dollars expended on home health care. Conversely, Medicare, the federal health insurance program for the nation’s elderly, contributes a negligible amount toward the cost of care in either setting. Medicare payments for nursing home stays amounted to less than $1 billion in 1988, and program expenditures for home health care services totaled $2.6 billion (U.S. Bipartisan Commission on Comprehensive Health Care, 1990).

The burden of providing long-term care in any setting, as compared with acute care and other health care services, is disproportionately borne either by the persons needing the care or by their families. In 1988, 43% of all spending on long-term-care services was financed through out-of-pocket payments by persons or families. Private insurers and private organizations furnished a little more than 3% of all payments for long-term-care ser-

Table 1
National Long-Term-Care Expenditures by Source, 1988a

<table>
<thead>
<tr>
<th>Source of Spending</th>
<th>Dollars (in billions)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Nursing Home Care</strong></td>
<td></td>
</tr>
<tr>
<td>Medicaid</td>
<td>19.2</td>
</tr>
<tr>
<td>Medicare</td>
<td>0.8</td>
</tr>
<tr>
<td>Other federal programs</td>
<td>1.0</td>
</tr>
<tr>
<td>Other state programs</td>
<td>0.1</td>
</tr>
<tr>
<td>Out-of-pocket payments</td>
<td>20.8</td>
</tr>
<tr>
<td>Private insurers and private organizations</td>
<td>1.3</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>43.3b</td>
</tr>
<tr>
<td><strong>Home Care</strong></td>
<td></td>
</tr>
<tr>
<td>Medicaid</td>
<td>3.3</td>
</tr>
<tr>
<td>Medicare</td>
<td>2.6</td>
</tr>
<tr>
<td>Other federal programs</td>
<td>0.6</td>
</tr>
<tr>
<td>State programs</td>
<td>0.5</td>
</tr>
<tr>
<td>Out-of-pocket payments</td>
<td>2.1</td>
</tr>
<tr>
<td>Private insurers and private organizations</td>
<td>0.6</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>9.7</td>
</tr>
<tr>
<td><strong>Total long-term-care expenditures</strong></td>
<td>52.8</td>
</tr>
</tbody>
</table>

bNumbers do not total due to rounding.
to elderly persons who require assistance with activities of daily living (e.g., eating, toileting, bathing, dressing) or instrumental activities of daily living (e.g., doing the housework and laundry, preparing meals, shopping for groceries).

Although support for long-term-care services from public programs does exist and in fact involves substantial amounts of public funds, these efforts are uncoordinated and skewed inordinately toward institutional care. Many federal programs provide long-term-care assistance either directly or indirectly, through the provision of cash, goods and services, or in-kind transfers (U.S. Senate, Special Committee on Aging, 1989).

As previously noted, Medicare and Medicaid constitute the major focus of public support for community-based and institutional long-term-care services. As currently structured, however, neither program lends itself to the furnishing of appropriate or effective long-term-care services, nor are they structured to optimize occupational therapy intervention. Medicare covers up to 100 days of care in a nursing home under the skilled nursing facility benefit, but eligibility standards require the beneficiary to be in need of daily skilled nursing or rehabilitation care. Only one third of all elderly persons who enter nursing homes meet these requirements (U.S. Bipartisan Commission on Comprehensive Health Care, 1990).

Additionally, beneficiary cost sharing commences after 20 days, and the daily rate, pegged at a percentage of the Medicare hospital deductible, generally exceeds the daily cost of nursing home care. Consequently, even those who meet the eligibility requirements do not benefit from the coverage. Similarly, Medicare's home health care benefit is limited to those who are homebound and in need of skilled nursing or rehabilitation care. These criteria again restrict eligibility as well as the scope and duration of services available. Occupational therapy services are particularly restricted under the Medicare home health care benefit. A beneficiary must be in need of a qualifying service (i.e., skilled nursing, physical therapy, or speech-language pathology) before occupational therapy may be provided. This current construction of the law, which denies access to those who may need only occupational therapy, can result in the unnecessary use of qualifying services, recurring disability, and unnecessary hospitalization or nursing facility placement.

The Medicaid program, while being the primary public source of nursing home care, is a payer of last resort. Eligibility criteria through asset and income limitations virtually mandate impoverishment in order to receive coverage. Changes enacted by Congress in 1989 established protection against impoverishment for the spouses of nursing home residents, but this limited protection does little for the 87% of those residing in nursing facilities who are single and must forfeit all assets and income to qualify (U.S. Bipartisan Commission on Comprehensive Health Care, 1990). A 1988 survey performed by the American Occupational Therapy Association (AOTA) revealed that of the 50 states and 3 U.S. territories providing Medicaid programs, only 31 states and the District of Columbia provided coverage for occupational therapy services in nursing facilities (AOTA, 1990).

States are also required to provide home care services through Medicaid, but are granted wide latitude in establishing eligibility, payment rates, and duration and scope of services. This results in substantial variation between states and an overall low rate of home health care expenditures under the program. All state Medicaid programs combined provided home health care services to only 593,000 persons in fiscal year 1986 (U.S. Congress, House Committee on Energy and Commerce, 1988). According to data collected by the AOTA Medicaid program survey, only 30 states and the District of Columbia provided coverage of occupational therapy services in the home health care setting, and many of these impose arbitrary utilization controls, such as limitations on numbers of visits or on dollar volume of billed services.

Figure 1. Breakdown of persons serving as informal caregivers of disabled elderly persons in the community in 1984 (U.S. Bipartisan Commission on Comprehensive Health Care, 1990). Note: The term disabled elderly refers to elderly persons who require assistance with activities of daily living (e.g., eating, toileting, bathing, dressing) or instrumental activities of daily living (e.g., doing the housework and laundry, preparing meals, shopping for groceries).
Besides Medicare and Medicaid, two other federal programs authorize an array of in-home and community-based long-term-care services for the elderly—the Social Services Block Grant program authorized under Title XX of the Social Security Act (Public Law 93-647) and the Older Americans Act (Public Law 89-73).

The Title XX program allocates federal funds according to a formula based on state population. States are allowed flexibility in establishing eligibility, which generally restricts participation to low-income categories. And because the Social Security Block Grant program's mission is to furnish a range of services to various populations, it faces competing demands and can provide only limited services to the elderly in need of long-term care. In addition, Title XX funding levels have declined in real terms since 1980 (O'Shaughnessy & Price, 1988).

The Older Americans Act also funds a broad array of supportive services for the elderly, such as homemakers and home health aide services, chore maintenance assistance, and nutrition services. Though services under this act are provided without the restrictions imposed by Medicare and without the asset and income tests required by Medicaid, overall funding and the number of people served are limited. Most of the act's funding goes to the support of nutritional services, senior centers, and community service employment (U.S. Senate, Special Committee on Aging, 1989).

Public Reform Trends

Although the question of how to construct and finance a more comprehensive long-term-care system has moved to the forefront of the health policy debate, the concern and attention is not new. Creation of federal task forces on long-term-care issues as well as federal investment in research and demonstration projects to identify cost-effective alternatives dates back to the late 1960s and early 1970s (O'Shaughnessy & Price, 1988). An awareness among policymakers that existing programs render only limited support for noninstitutionalized care as well as a concern about fragmentation and lack of coordination in federal efforts has led to a proliferation of new proposals. Congress has, however, proceeded cautiously and taken an incremental approach to the expansion of home- and community-based care.

Over the past decade, the Medicaid program has become the principal laboratory for Congress's exploration of alternative models for the provision of long-term-care services. In 1981, as part of the Omnibus Budget Reconciliation Act (Public Law 97-35), Congress established a new option for states desiring to use innovative methods of providing home- and community-based services. Under this Section 2176 waiver program, the federal government can waive certain provisions of Medicaid law to allow a state to develop cost-effective alternatives for providing services or reimbursement. States may provide coordinated, noninstitutionalized services for specific groups of persons who are at risk of institutionalization or who are in institutions and need assistance for placement back in the community (U.S. Congress, House Committee on Energy and Commerce, 1988).

The Section 2176 waiver program allows states to target populations identified as needing extended care, such as elderly persons or persons with disabilities, mental retardation, or chronic mental illness. States can limit the overall number of people receiving services, restrict the program to certain geographic areas, include optional services not covered under their standard Medicaid program, and provide nonmedical services. Optional services that may be provided include homemaker, home health aide, and personal care services; medical day-care services; hospice care; and partial hospitalization and clinical services for persons with chronic mental illness. A state may also cover specific social or medical-social services that ordinarily would not be covered by Medicaid, including respite care, habilitation services, and psychosocial rehabilitation. States' use of the Section 2176 waiver programs is, however, constrained by budget neutrality requirements. That is, the average per capita costs for services furnished under a waiver cannot exceed the costs that would have been incurred had the person been institutionalized. In many states with limited nursing home vacancies, a cost savings is difficult to verify; many potential waiver program participants could not have entered a nursing facility anyway due to a lack of available space (U.S. Congress, House Committee on Energy and Commerce, 1988).

The most recent data available indicate that 42 states had a total of 87 regular Section 2176 programs operating. Of these 87 programs, 42 are targeted to persons who are elderly and disabled; although only 79,000 persons within that population were actually served nationwide (U.S. Congress, House Committee on Energy and Commerce, 1988).

Although no published data allow an assessment of the scope of use of occupational therapy services nationally under Section 2176 waiver programs, this authority does offer an alternative to conventional service provision systems for occupational therapy intervention. Further, to the extent that these waivers may be the building blocks for an incremental expansion of broader long-term-care coverage by Congress, efforts to foster greater understanding of and participation in these programs by occupational therapy practitioners will be extremely important (see Table 2).

In an effort to address the difficulty that states with limited nursing home beds have in participating in the Section 2176 program, Congress established a second home- and community-based services program targeted specifically to elderly persons. This Section 1915(d) waiver program, created by the Omnibus Budget Reconciliation Act of 1987 (Public Law 100-203), is available only...
would be likely

Nole

would actually occupy a Medicaid nursing home bed in

Delaware 2 AID, MRJDD

Georgia 1 AID 2

South Dakota 1 MRJDD

Texas's project that promotes community services in
place of nursing home care. The success of Califor­
ia's On Lok demonstration led Congress in 1986 to
authorize replication of similar projects aimed at the
frail elderly in other cities (Omnibus Budget Reconcili­
ant Act of 1986 [Public Law 99-509]) (US, Congress,
House Committee on Energy and Commerce, 1988)],
which provides health and social services on a prepaid
basis to frail elderly persons at risk of institutionaliza­
tion; New Jersey's respite care pilot project, which pro­
vides support services for family caregivers to prevent
the institutionalization of elderly and disabled persons;
ad Texas's project that promotes community services
services through various tax incentives. Some of the
major proposals recently crafted by key health care poli­
cymakers in Congress are described below.

Elder Care Long-Term Assistance Act (H.R. 3140).
This act, introduced by Representative Henry Waxman
(D-CA), would amend the Medicare program to pro­
provide long-term care. These proposals vary in their approaches and contain differing benefits,
financing mechanisms, and administrative features. Many
of them focus on home- and community-based care, oth­
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evolution of health policy. Past demonstration projects have included prospective payment for inpatient hospital
services and the first primary care case-management
programs. Some demonstrations have been mandated
by Congress and others have been approved at the
discretion of the secretary of the U.S. Department
of Health and Human Services. Examples of long-term-
care demonstrations include California's On Lok
program in San Francisco (Capitation Reimbursement
for Comprehensive Long-Term Care [U.S. Congress,
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chronically ill children, Mf
ment for home and community services would depend
on the person's degree of limitations in activities of daily
living or cognitive impairment, and coverage would be
limited to an average of 30 hr per week. The measure
would cover two thirds of the cost of nursing home care
after the first 60 days for a period of 2 years. Subsequent­
ly, the beneficiary could be responsible for 10% of the cost

for coverage of beneficiaries aged 65 years or older who
would be likely to require nursing home care. It exempts
states from limiting program participants to persons who
would actually occupy a Medicaid nursing home bed in
the absence of a waiver. States must agree, however, to
put themselves at financial risk by accepting a ceiling on
the total federal Medicaid funds they receive for long-
term-care services for the elderly, both those institution-
ized and those in the waiver program. Only Oregon has
pursued this waiver option to date (U.S, Congress, House

Other long-term-care initiatives have been under-
taken as demonstration projects under waiver authority
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Table 2
Section 2176 Waiver Programs in Operation, February
1988

<table>
<thead>
<tr>
<th>State</th>
<th>Number</th>
<th>Population Served</th>
<th>Model Waivers</th>
</tr>
</thead>
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<tr>
<td>Alabama</td>
<td>2</td>
<td>A/D, MR/DD</td>
<td></td>
</tr>
<tr>
<td>California</td>
<td>4</td>
<td>A/D, MR/DD</td>
<td></td>
</tr>
<tr>
<td>Colorado</td>
<td>2</td>
<td>A/D</td>
<td></td>
</tr>
<tr>
<td>Connecticut</td>
<td>4</td>
<td>A/D</td>
<td></td>
</tr>
<tr>
<td>Delaware</td>
<td>2</td>
<td>A/D, MR/DD</td>
<td></td>
</tr>
<tr>
<td>Florida</td>
<td>3</td>
<td>A/D, MR/DD</td>
<td></td>
</tr>
<tr>
<td>Georgia</td>
<td>4</td>
<td>A/D, MR/DD</td>
<td></td>
</tr>
<tr>
<td>Hawaii</td>
<td>4</td>
<td>A/D, MR/DD, AIDS</td>
<td></td>
</tr>
<tr>
<td>Idaho</td>
<td>3</td>
<td>A/D, MR/DD</td>
<td></td>
</tr>
<tr>
<td>Illinois</td>
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<td>A/D, MR/DD</td>
<td></td>
</tr>
<tr>
<td>Indiana</td>
<td>3</td>
<td>A/D, MR/DD</td>
<td></td>
</tr>
<tr>
<td>Iowa</td>
<td>1</td>
<td>A/D</td>
<td></td>
</tr>
<tr>
<td>Kansas</td>
<td>1</td>
<td>A/D, MR/DD</td>
<td></td>
</tr>
<tr>
<td>Kentucky</td>
<td>1</td>
<td>A/D</td>
<td></td>
</tr>
<tr>
<td>Louisiana</td>
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<td>A/D, MR/DD</td>
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<td></td>
</tr>
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<td>Maryland</td>
<td>3</td>
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<td>Massachusetts</td>
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<td>A/D</td>
<td></td>
</tr>
<tr>
<td>Michigan</td>
<td>1</td>
<td>A/D</td>
<td></td>
</tr>
<tr>
<td>Minnesota</td>
<td>1</td>
<td>A/D, MR/DD</td>
<td></td>
</tr>
<tr>
<td>Mississippi</td>
<td>1</td>
<td>A/D</td>
<td></td>
</tr>
<tr>
<td>Missouri</td>
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<td>A/D, MR/DD</td>
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</tr>
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<tr>
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<td>New Jersey</td>
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<td>A/D, MR/DD, AIDS, &lt;2</td>
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<tr>
<td>New York</td>
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<td></td>
</tr>
<tr>
<td>North Carolina</td>
<td>2</td>
<td>A/D, MR/DD</td>
<td></td>
</tr>
<tr>
<td>North Dakota</td>
<td>2</td>
<td>A/D, MR/DD</td>
<td></td>
</tr>
<tr>
<td>Ohio</td>
<td>2</td>
<td>A/D, MR/DD</td>
<td></td>
</tr>
<tr>
<td>Oklahoma</td>
<td>2</td>
<td>A/D</td>
<td></td>
</tr>
<tr>
<td>Oregon</td>
<td>2</td>
<td>A/D, MR/DD</td>
<td></td>
</tr>
<tr>
<td>Pennsylvania</td>
<td>2</td>
<td>A/D, MR/DD</td>
<td></td>
</tr>
<tr>
<td>Rhode Island</td>
<td>1</td>
<td>A/D</td>
<td></td>
</tr>
<tr>
<td>South Carolina</td>
<td>1</td>
<td>A/D</td>
<td></td>
</tr>
<tr>
<td>South Dakota</td>
<td>1</td>
<td>A/D, MR/DD</td>
<td></td>
</tr>
<tr>
<td>Tennessee</td>
<td>3</td>
<td>A/D, MR/DD</td>
<td></td>
</tr>
<tr>
<td>Texas</td>
<td>1</td>
<td>A/D</td>
<td></td>
</tr>
<tr>
<td>Utah</td>
<td>1</td>
<td>A/D, MR/DD</td>
<td></td>
</tr>
<tr>
<td>Vermont</td>
<td>2</td>
<td>A/D, MR/DD, MI</td>
<td></td>
</tr>
<tr>
<td>Virginia</td>
<td>1</td>
<td>A/D</td>
<td></td>
</tr>
<tr>
<td>Washington</td>
<td>2</td>
<td>A/D, MR/DD</td>
<td></td>
</tr>
<tr>
<td>West Virginia</td>
<td>2</td>
<td>A/D, MR/DD</td>
<td></td>
</tr>
<tr>
<td>Wisconsin</td>
<td>2</td>
<td>A/D, MR/DD</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>87</td>
<td></td>
<td>20</td>
</tr>
</tbody>
</table>

Note: A/D = aged/disabled, MR/DD = mentally retarded/developmentally disabled, AIDS = acquired immuno­
deficiency syndrome/AIDS-related complex, <21 = chronically ill children, MI = mentally ill.

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of care. Financing of the new benefits would be achieved through elimination of the cap on wages subject to the Medicare and Social Security payroll tax.

**Long-Term Care Protection Act (S. 2163 and H.R. 4093).** These proposals, introduced by Senator Edward Kennedy (D-MA) and Representative Mary Rose Oakar (D-OH), respectively, would amend the Public Health Service Act to provide comprehensive coverage for nursing home and home- and community-based care services for persons 65 years of age or older, persons with disabilities on Medicare, or persons under 19 years of age who are functionally dependent in at least two or more activities of daily living. The program would, like Medicare, have two parts. Part A (mandatory participation) would provide 6 months of nursing home care and community-based care with modest copayments. Part B (optional participation) would cover nursing home stays that exceed 6 months. Persons could enroll at the age of 45 years or 65 years, with a separate and lower premium for those entering at the earlier age. Part B would cover 65% of the costs of nursing home care. The beneficiary, through out-of-pocket spending, insurance, or Medicaid, would cover the balance. Financing would be through elimination of the cap on income subject to the Medicare and Social Security payroll tax.

**Mediplan Act (H.R. 5300).** This act, introduced by Representative Fortney Stark (D-CA), amends the Social Security Act to provide universal health insurance and long-term-care services. It would furnish nursing home care to those who are dependent in at least three activities of daily living and home- and community-based care for persons dependent in at least two activities of daily living. When fully implemented, it would cover comprehensive nursing home care after a 2-month deductible. Home- and community-based benefits would cover home health care, homemaker, and personal care services as well as adult day care. All benefits would require a 20% copayment. Persons with incomes below 200% of the federal poverty level would be exempt from the deductible and copayments. Financing would be achieved through a new 4% tax on all individual and corporate income.

**Long-Term Care Assistance Act (S. 2305).** This act, introduced by Senator George Mitchell (D-ME), amends Medicare to provide coverage of long-term home care services, home- and community-based respite care, and long-term nursing home services for qualified beneficiaries who are functionally dependent in at least two activities of daily living. Beneficiaries would be eligible for coverage of nursing home care after a 2-year stay in an approved facility, with a 50% cost-sharing requirement. The bill would impose a $500 deductible for home health care, with a 20% copayment. Respite care is subject to a 50% copayment, with a $2,000 cap per year. Financing would be achieved through a combination of beneficiary premium increases, copayments, estate and gift taxes, and elimination of the cap on income subject to the Medicare payroll tax.

All of these legislative proposals incorporate many common themes. Occupational therapy is covered in the home-based, community-based, and nursing facility benefits that all of these proposals would establish. All of the proposals generally rely on case-management agencies to oversee comprehensive needs assessments and to coordinate care plan development. The measures also use varying degrees of activities of daily living deficiency and cognitive impairment as the determinants for eligibility, and they mandate screening through assessments conducted by multidisciplinary teams of health care professionals and the use of uniform assessment instruments.

Many other legislative proposals relating to long-term care have been introduced in Congress in recent years. Those outlined above, however, represent recent measures advanced by key health policymakers who chair congressional committees or subcommittees with legislative jurisdiction over the long-term-care issue. The current views of these policymakers, as embodied in their respective proposals, are reliable indicators of the possible structure and scope of any future system of long-term care.

**The Pepper Commission**

Responding to a heightened sense of public concern over access to health care and the long-term-care problem, Congress established the U.S. Bipartisan Commission on Comprehensive Health Care as part of the Medicare Catastrophic Coverage Act of 1988 (Public Law 100-360). Referred to as the Pepper Commission after the late representative Claude Pepper (D-FL), who was the driving force behind its creation and the panel’s first chairman, the Commission was established to study and make recommendations on how to achieve comprehensive health care for all Americans and how to construct and finance a system of long-term care. Although most portions of the ill-fated catastrophic legislation were repealed approximately 18 months after enactment, the provision establishing the Commission was retained. Those responsible for its creation hoped that the Commission’s work would contribute substantially to the development both of a policy and of political consensus on addressing the nation’s long-term-care needs. Comprising 12 members of Congress and 3 members appointed by President Reagan, the Commission met and held public hearings around the country for almost 2 years and analyzed broad options for dealing with the long-term-care problem, including expansion of existing programs such as Medicaid, the promotion of private insurance, and the establishment of a new social insurance program.

AOTA, along with other members of the National Rehabilitation Caucus, a coalition of associations repre-
senting health care professionals, providers, and consumer groups, presented joint testimony to the Commission. Their testimony outlined the serious deficiencies in existing long-term-care services relating particularly to access to occupational therapy and other rehabilitation services and highlighted several principles that AOTA viewed as fundamentally important to the Commission’s deliberations and final recommendations. Among the recommendations were the following:

1. The objective of any program of long-term care should be to allow its beneficiaries to continue to live a life of quality and dignity, with emphasis on independence, autonomy, and responsibility.
2. Eligibility for long-term-care assistance should not be determined by age, income, or other resources, but rather, by a measure of the person’s ability to perform activities of daily living as well as his or her degree of mobility and communication.
3. Coverage should be universally assured for all populations, and no one should be excluded due to preexisting conditions.
4. Long-term-care benefits should cover a comprehensive, defined spectrum of appropriate rehabilitation and social services, both institutional and home- or community-based, without financial bias toward any setting.
5. Continuity of care and coordination of services should be assured through appropriate case management, with full participation by qualified rehabilitation professionals.
6. Support from family members and other informal caregivers should not jeopardize a person’s eligibility for necessary formal services, and adequate provision for respite care must be included.

The Pepper Commission issued its final report in September 1990. Many of the principles enumerated by AOTA and other caucus members were incorporated into the Commission’s recommendations. As a means of allocating public resources most effectively, assuring people of all incomes adequate protection, and striking a balance between the public and private sector roles, the Commission outlined a limited social insurance program. This blueprint integrates a new public program of home- and community-care benefit, services would be available to eligible beneficiaries living in boarding and nursing care facilities and other types of assisted living as well as those living in private homes. Nursing home coverage would be provided for the first 3 months of care with full protection of a person’s income and assets. Both skilled and custodial care would be provided.

Under both the home- and community-care benefit and the 3-month nursing home benefit, beneficiaries would be responsible for a 20% copayment, with federal subsidies for those with incomes below 200% of the federal poverty level.

Eligibility would be determined by a state or local government or nonprofit assessment agency with the use of standardized assessment criteria. Case managers would oversee development of individual care plans and determine the scope and mix of services tailored to the beneficiary’s needs.

Services authorized under the public program would include skilled nursing, occupational therapy, physical therapy, and speech-language pathology as well as a broad range of personal care and homemaker chores. Services, medication management, and day care for disabled adults and children. Respite care and training of family members in the provision of home-based care and supportive counseling for family caregivers would also be included.

Under the home- and community-based care benefit, services would be available to eligible beneficiaries living in boarding and nursing care facilities and other types of assisted living as well as those living in private homes. Nursing home coverage would be provided for the first 3 months of care with full protection of a person’s income and assets. Both skilled and custodial care would be provided.

Finally, the Commission concluded that the federal government should increase funding or redirect existing funds for research and development efforts aimed at preventing, delaying, and dealing with long-term illnesses and disabilities. The effort should include research on outcome measures and national practice guidelines in long-term care.
Outlook for Long-Term-Care Reform

The Pepper Commission's recommendations received mixed reactions. Most observers applauded the Commission's work in more clearly defining the nature and scope of long-term-care needs, and many endorsed the combination of social insurance and income protection, which constitute their benefit package. Many believed that the Commission's fundamental failing, however, was its inability to achieve an agreement on specific recommendations for financing the proposals. The recommendations in the Commission's report would result in a net new federal cost of $42.8 billion, that is, $24 billion for home and community care and $18.8 billion for nursing home care.

The enormous cost of comprehensive long-term care along with the parallel and competing need to address the problems of the millions of Americans without health insurance coverage will remain the primary stumbling block to significant progress. The current fiscal environment, which involves huge federal budget deficits and many competing and pressing social needs, allows only for incremental progress toward the provision of a broader range of long-term-care services for the elderly.

One additional incremental step was taken at the end of 1990, when Congress approved a new optional program under Medicaid through which states may cover home and community care for the functionally disabled elderly (Omnibus Budget Reconciliation Act of 1990 [Public Law 101-508]). Advanced by Pepper Commission Chairman Senator John D. Rockefeller (D-WV), the measure does not contain the budget neutrality requirements that constrained states under the Medicaid Section 2176 waiver program.

AOTA has undertaken specific initiatives to broaden understanding of long-term-care issues and to foster leadership skills within the profession to facilitate participation in policy making and long-term-care system design. Representative Assembly action in 1990 led to the Executive Board's appointment of a Long-Term-Care Task Force. The task force's charge is to develop educational plans and materials for practitioners and educational programs to address emerging long-term-care issues. In addition, in 1992, the Executive Board's Ad Hoc Committee on Leadership will oversee implementation of an in-depth, multiphased training initiative on advocacy and leadership in long-term care that will focus on consumers, providers, and systems.

Although a comprehensive federal program of long-term care will probably not occur in the near future, increased concerns and demands by their constituencies will maintain congressional interest and emphasis on exploring alternatives to traditional long-term care. The challenge to the occupational therapy profession will be to continue asserting and defining its role as an essential component of long-term care and to maintain a voice in the evolving public policy debate on the development of alternatives. To achieve these goals will require a sustained activism in the legislative and political arenas at both the state and national levels. A renewed commitment on the part of individual practitioners to a strong and effective state association presence in state legislatures, continued support for a national voice in Congress, and a willingness to participate in grass-roots lobbying efforts and political action will all be critical in the assurance of a central role for occupational therapy in meeting the needs of the nation's long-term-care population.

References


