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The Aging Services Network: Accomplishments and Challenges in Serving a Growing Elderly Population

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OVERVIEW — In 1965, Congress enacted the Older Americans Act, establishing a federal agency and state agencies to address the social services needs of the aging population. The mission of the Older Americans Act is broad: to help older people maintain maximum independence in their homes and communities and to promote a continuum of care for the vulnerable elderly. In successive amendments, the Act created area agencies on aging and a host of service programs. The "aging services network," broadly described, refers to the agencies, programs, and activities that are sponsored by the Older Americans Act. The Act's funding for services is supplemented by other federal funds, such as Medicaid, as well as state and local funds. As the number of older people increases with the aging of the baby boom population, the need for a wide spectrum of services is expected to place pressure on aging services. Whether the aging services network will be able to sustain its momentum and fully realize its potential will depend on its ability to attract and retain additional resources.



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The Aging Services Network: Accomplishments and Challenges in Serving a Growing Elderly Population

In 1965, when Medicare, Medicaid, and the Older Americans Act were enacted, people age 65 and older represented slightly more than 9 percent of the nation's population. By 2006, the number of elderly had more than doubled, reaching 37.3 million people and 12.4 percent of the U.S. population. The first wave of the baby boom generation turned age 60 in 2006 and will turn age 65 in 2011—the year the Older Americans Act is due for reauthorization. By 2020, almost one in six people will be age 65 and older. The growing elderly population is a recurrent and persistent theme in policy deliberations on the future of federal health, long-term care, and income security programs. In addition to concern about the fiscal pressures affecting Medicare and Medicaid, policymakers and practitioners have expressed concern about the limited resources available under the Older Americans Act, given its broad mission.

The purpose of the Older Americans Act is to help older people maintain maximum independence in their homes and communities, with appropriate supportive services, and to promote a continuum of care for the vulnerable elderly. The 1965 Act represented a turning point in financing and delivering community services to the elderly. Before then, federal and state governments played a limited role in providing social services and long-term care to older people.

The Act's reach has evolved significantly through the years. Initially, it created authority for a then-new Administration on Aging (AoA) within the U.S. Department of Health and Human Services (HHS) as well as state agencies to be responsible for community planning for aging programs and to serve as catalysts for improvement in the organization, coordination, and delivery of aging services in their states. It also created authority for research, demonstration, and training projects in the field of aging. Over the succeeding years, Congress expanded the scope, authority, and responsibilities of these agencies. The original legislation authorized generic social service programs, but in successive amendments, Congress authorized more targeted programs under various titles of the Act to respond to specific needs of the older population. In 1973, Congress extended the reach of the Act by creating authority for sub-state "area agencies on aging" to be responsible for planning and coordination of a wide array of services for older people, as well as serving as advocates on their behalf. Some observers have pointed out that the Act's funding has not kept pace with increasing responsibilities.

FIGURE 1 Major Services of the Aging Services Network

Aging Services Network

State & Area Agencies on Aging 56 State Agencies 655 Area Agencies Planning, Coordination, and Advocacy

1 1 1 1 1

Service Providers

Access to Services	Nutrition	Home & Community- Based Long-Term Care	Disease Prevention & Health Promotion	Vulnerable Elder Rights Protection
Outreach, Information and Assistance Regarding Service Benefits Care Management Transportation	Congregate and Home-Delivered Meals Nutrition Counseling and Education	Home Care, Chore, Personal Care Adult Day Care Family Caregiver Support	Examples: Physical Fitness Nutrition Counseling Immunizations	Long-Term Care Ombudsman Prevention of Elder Abuse, Neglect, and Exploitation Legal Assistance

Today, the "aging services network" is comprised of 56 state agencies on aging, 655 area agencies on aging, 233 tribal and Native American organizations, and two organizations serving Native Hawaiians, as well as nearly 30,000 local service provider organizations. These agencies are responsible for the planning, development, and coordination of a wide array of social, long-term care, and health-support services within each state (Figure 1).

The aging services network administers not only Older Americans Act funding, but also, at a state's option, funding under other federal programs, including Medicaid, the Social Service Block Grant (SSBG), the State Health Insurance Program (SHIP), and section 398 of the Public Health Service Act, as well as state and local funds.

This paper describes the functions and governance of the aging services network and its role in managing long-term care and health-support services funded by Titles III and VII of the Older Americans Act. It then discusses major services supported by other federal and state sources administered by the aging services network. (See Appendix for a summary of these services.)

THE OLDER AMERICANS ACT: THE FOUNDATION OF THE AGING SERVICES NETWORK

While the infrastructure created by the Older Americans Act laid the foundation for the current aging services network, the law was not intended to meet all the community service needs of older people. The resources made available under the Act are intended to leverage other federal and

nonfederal funding sources to serve older people. For example, in some states, state agencies on aging have been assigned responsibility for administering long-term care programs financed by Medicaid. State agencies on aging in some of these states have redesigned their Older Americans Act, Medicaid, and state long-term care programs to expand consumer choice in home and community-based services and to improve consumer access to the often complex web of community services. Building on the experience of these states, AoA has launched a series of discretionary grant initiatives in the past several years to help more states make systemic changes to help consumers plan for and gain access to home and community-based services.

Considering the broad sweep of its mission, the reach of the Act itself is constrained by limited resources. A relatively small proportion of the older population receives services directly funded by the Act. However, the infrastructure created by the Act can influence service programs that reach a far larger proportion of the older population. Mandates given to state and area agencies on aging to act as planning, coordinating, and advocacy bodies can impact policies that affect broad groups of older people. For example, state agency on aging actions to redesign long-term care systems have the potential to change service patterns for older people and for younger people with disabilities who do not directly receive services funded by the Older Americans Act. In addition, the advocacy functions embedded in the Act's programs can make other programs' activities more accountable. For example, actions taken by long-term care ombudsmen to assist nursing home residents can improve care paid for by Medicaid and Medicare.

As federal and state governments strive to meet growing needs, they have increasingly looked to the aging services network to administer new programs and services and to expand the scope of their responsibilities. For example, in implementing the Medicare Part D prescription drug benefit, the Centers for Medicare & Medicaid Services (CMS) has drawn heavily on the outreach and assistance capabilities of the aging network agencies. Whether the aging services network can continue its momentum and fully meet its potential in the face of growing demand will be influenced by its ability to attract and retain additional resources and by policy decisions of federal, state, and local officials.

STRUCTURE AND FUNDING OF THE OLDER AMERICANS ACT

The Older Americans Act contains seven titles and authorizes myriad service programs. Total federal funding for the Act's programs in fiscal year (FY) 2008 is \$1.9 billion. Excluding Title V (a subsidized employment program for people age 55 and over and outside the scope of this report), total federal funding for AoA and aging service network programs is \$1.4 billion. Figure 2 (next page) shows a description of each title and the breakdown of federal funding by title.

Total: \$1.924 billion TITLE VII 1.1% **TITLE VI** 1.7% **Vulnerable Elder Rights Grants for Native Americans Protection Activities** (\$33.2 million) (\$20.6 million) TITLE V 27.1% **TITLE III** 66.7% **Community Service Employment for Grants for State Older Americans** and Community (\$521.6 million) **Programs on Aging** (\$1,283.8 million) TITLE IV 0.8% **Nutrition Services** 39.6% Research, Training, and Demonstrations Disease Prevention (\$14.7 million) and Health Promotion 1.1% Family Caregiver Support TITLE II 2.6% 8.0% **Aging Network** Supportive Services **Support Activities** 18.3% (\$49.7 million)

FIGURE 2: Older Americans Act, FY 2008 Appropriations

Source: Prepared by the National Health Policy Forum, based on appropriations data in Angela Napili, "Older Americans Act: FY2008 Funding and FY2009 Budget Request," Congressional Research Service, Report RL33880, updated March 27, 2008.

	At a Glance: Older Americans Act Structure
Title I	Declaration of Objectives. Sets out broad social policy objectives oriented toward improving the lives of all older people.
Title II	Administration on Aging (AoA). Establishes AoA within the Department of Health and Human Services (HHS) as the chief federal agency advocate for older persons and sets out the responsibilities of AoA and the Assistant Secretary for Aging. Establishes aging network support activities.
Title III	Grants for State and Community Programs on Aging. Authorizes activities of state and area agencies on aging and funds for supportive and nutrition services, family caregiver support, and disease prevention and health promotion activities.
Title IV	Activities for Health, Independence, and Longevity. Authorizes research, training, and demonstration projects in the field of aging.
Title V	Community Service Senior Opportunities Act. Authorizes grants to support part-time employment opportunities for unemployed low income people age 55 and older who have poor employment prospects.
Title VI	Grants for Native Americans. Authorizes grants for supportive and nutrition services to American Indians, Alaskan Natives, and Native Hawaiians.
Title VII	Vulnerable Elder Rights Protection Activities. Authorizes grants for the long-term care ombudsman program and services to prevent elder abuse, neglect, and exploitation.

In general, AoA distributes Older Americans Act funds to states according to a population-based formula. Except for family caregiver support services, each state receives Title III allotments for services proportionate to its population age 60 and over, compared with the total U.S. population age 60 and over. Family caregiver support program funds are allotted based on states' proportionate population age 70 and over. States allocate Older Americans Act funds to area agencies on aging based on a state-determined formula, which is generally a combination of population factors such as age, income, and racial or ethnic status of the older population throughout the planning and service areas of the state.

Targeting the Vulnerable Older Population

While Older Americans Act services are available to all people age 60 and over who need assistance, the law requires that services be targeted to those with the greatest economic or social need. In successive amendments, Congress has added specific groups of older people to be targeted: those with low income, members of minority or ethnic groups, older people living in rural areas, those at risk for institutional care, and those with limited English proficiency.²

Means testing—considering a person's income, assets, savings, or personal property as a condition of receiving services—is prohibited.³ Participants are encouraged to make voluntary contributions for services they receive in order to expand services to others. In addition, states may implement cost-sharing policies for certain services (such as homemaker, personal care, or adult day care services) on a sliding fee scale, based on income and the cost of services. Older people may not be denied services due to failure to make voluntary contributions or cost-sharing payments, where such policies exist.

Although the distribution of funds to states is determined on the basis of age alone, states and area agencies determine how to serve the target populations as defined by federal law. A variety of methods are used to target services, including location of services in areas where vulnerable people reside, as well as strategic outreach to low-income and minority older people. Some services are targeted to vulnerable groups by definition. Examples of these, the long-term care ombudsman program, family caregiver support services, home and community-based long-term care services, and assisted transportation to those with limited mobility, are discussed below.

Population served — For FY 2006, AoA data show that about 6 percent of the 50.8 million people age 60 and older, or about 3 million people, received services funded by the Act, such as home-delivered meals, home care, and case management, on a regular basis. A larger proportion — about 20 percent of the older population, or about 10 million people — received other services such as transportation, information and assistance, or congregate meals on a "less than regular" (occasional) basis. In addition, Title III provided support services to almost 700,000 family caregivers.

Even though a small number overall receives services, vulnerable older people receive a disproportionate share of services. Of all people served under Title III programs, in FY 2006, 27 percent had income below the federal poverty

Although its services are available to all people over age 60, the Older Americans Act requires that services be targeted to those most in need.

level (FPL), compared with 9.7 percent in the total population age 60 and over in poverty. Further, about 19.8 percent of clients were members of a minority group, compared with about 15 percent in the total population age 60 and over. Over one-third of people served lived in rural areas.

In many cases, state and local communities provide matching funds above the federal requirements to spread Older Americans Act funds more widely. In addition, voluntary contributions from older people to pay part of the costs of services, especially for the nutrition program, augment federal, state, and local funds.

State and Area Agencies on Aging: Functions, Governance, and Staffing

Since their inception, the major functions of state and area agencies have been to promote "comprehensive and coordinated services systems" and "maximum independence and dignity in a home environment with appropriate support services" for older people. These agencies are also charged with acting as advocates to encourage a "continuum of care" for vulnerable older people and to help them remain as independent as possible in home and community-based settings.⁵

Each state has an agency designated by the governor to plan and coordinate services for older people, develop a statewide plan on aging, and administer Older Americans Act programs. State agencies on aging are required to divide the state into planning and services areas (PSAs), and, for all PSAs, designate area agencies on aging that develop area plans on aging and plan and coordinate services. State and area agency plans on aging are to reflect how the plans will meet the older peoples' needs, using both Older Americans Act funds as well as other funding resources. Area agencies contract with a wide variety of community service providers to deliver Older Americans Act–funded services, but they may also provide services directly if the state agency grants a waiver.

About half of state agencies on aging are located in state health and/or human services agencies; the remainder are independent departments or commissions of state government.⁶ The governance of area agencies on aging varies widely. According to a 2006 study, 41 percent of area agencies were private nonprofit organizations, 32 percent were part of county or city county governments, 25 percent were part of councils of government, and 2 percent were Indian tribal organizations or other entities.⁷

Staffing of area agencies also varies considerably, from relatively small staffs, especially in rural areas, to very large staffs in major metropolitan areas. In part, this reflects state policy decisions regarding geographic distribution of area agencies, the dispersion of the elderly population within a state, and funding. In FY 2006, the 655 area agencies on aging were staffed by over 22,000 paid staff; volunteers numbered over 20,000 people. The variation in the governance as well as the staff and resources available contributes to wide differences in capacity among area agencies.

Expanding Responsibilities of State and Area Agencies on Aging

The original legislation, and subsequent legislation in the 1970s, emphasized the planning, coordination, and needs-identification functions of state and area agencies that continue as major functions today. The functions of the state and area agencies on aging were designed to be carried out through a "bottom-up planning" process. The development of the aging services infrastructure in the early 1970s was partially influenced by national political trends toward decentralization of decision-making to state and local governments, exemplified by the New Federalism of the Nixon administration. It was believed that state and area agencies were in the best position to assess the needs of the elderly and to plan and coordinate services at their respective levels without federal directives on what services to provide. While the program goals were determined nationally, the program was to be state-administered with a great deal of state and local flexibility.

FIGURE 3: Acronyms Defined

AoA Administration on Aging

AAA Area Agencies on Aging

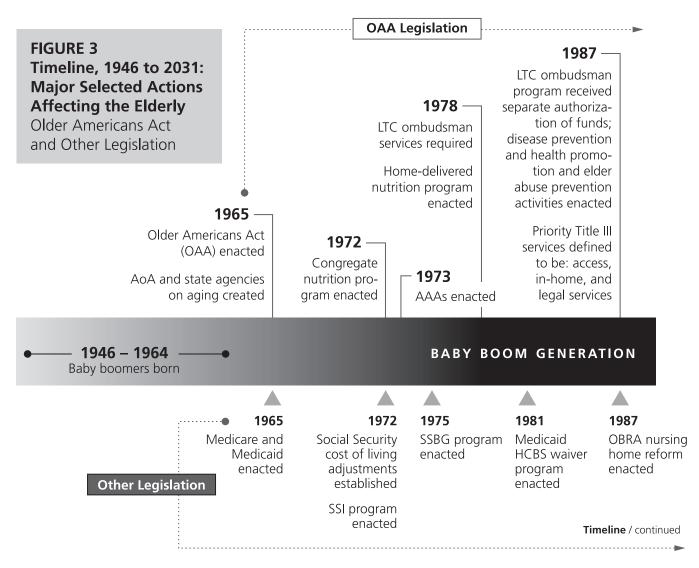
HCBS Home and Community-Based Services

LTC Long-Term Care

OBRA Omnibus Budget Reconciliation Act

SSBG Social Service Block Grant

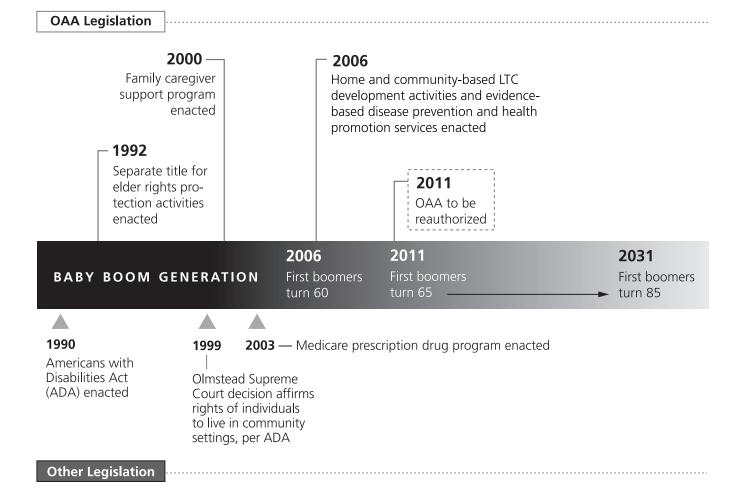
SSI Supplemental Security Income



During the early years of implementation, Congress authorized limited dollars for social services and intended funds were to act as catalysts, or "seed money" for drawing in state and local (non-Older Americans Act) funds to benefit the elderly. The decentralized planning and service model has meant that state and local agencies, working collectively within a state, are largely in control of their aging agendas, and can be responsive to state and local needs, within federal guidelines and funding priorities. However, the flexibility given to state and area agencies on aging has also led to wide variability in the design, implementation, and scope of aging services programs they administer, outside the federally authorized Older Americans Act programs. Moreover, the aging network's success in securing additional resources has depended on the political and economic circumstances in individual states and localities, and the ability to leverage private sector funds.

As state and area agencies implemented the planning process during the 1970s and 1980s, the needs of older people became more identified and

FIGURE 3 — Timeline / continued



differentiated. At the same time, Congress began to authorize targeted programs to respond to specific needs. (See Figure 3, pp. 10 and 11, for a timeline of major events in the evolution of the Older Americans Act, as well as related legislation affecting the elderly.) The congregate and home-delivered nutrition services programs, created to address issues of nutritional inadequacy among the elderly, were added to the Act in 1972 and 1978, respectively. The long-term care ombudsman program was added in 1978 to address issues affecting residents of long-term care facilities. In 1987, Congress required states to devote a portion of Title III services funds to certain "priority" services: (i) access services, defined as transportation services, outreach, information, and assistance to help older people obtain services, and case management; (ii) in-home services; and (iii) legal assistance. Also in 1987, the disease prevention and health promotion program was authorized. In 2000, the family caregiver support program was enacted. In the latest amendments in 2006, Congress recognized the role that the aging services network can play in promoting use of home and community-based long-term care services for people who are at risk for institutional care. These amendments required AoA to implement Aging and Disability Resource Centers (ADRCs) in all states to serve as visible and trusted sources of information on long-term care options and to coordinate and streamline consumer access to services (see below for information on ADRCs).

Generally, evaluations of individual Older Americans Act programs contain positive findings. However, with a few exceptions, evaluations are limited to overviews of program implementation, or are dated. While core Older Americans Act programs are administered by all state and area agencies, some observers have pointed to the wide variability in the design, implementation, and scope of aging services available to older people among states and across communities within states. For many social services, national standards or guidelines for best practices do not exist. This can present challenges to state and local aging service administrators who may seek to achieve or approximate effectiveness as measured by any defined standards.

SERVICES AUTHORIZED BY THE OLDER AMERICANS ACT

Title III authorizes four service programs: supportive services, nutrition services, family caregiver support, and disease prevention and health promotion activities. Title VII authorizes the long-term care ombudsman program, and activities to prevent elder abuse, neglect, and exploitation. A discussion of these programs follows (see also Appendix for a summary).

Supportive Services: Wide Range of Services to Help Older People Remain Independent in Their Communities

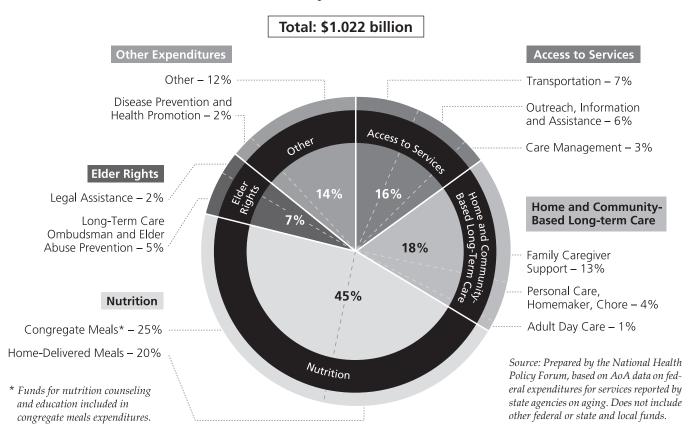
The supportive services program funds social services aimed at helping older people remain independent in their own homes and communities. Unlike other programs under the Older Americans Act that target a specific service,

this program funds a wide range of services. These include services to help older people access services (such as transportation, outreach, information and assistance, and case management) as well as home and community-based long-term care services (such as personal care, homemaker, chore, and adult day care services). Due to its limited funding, the amount of services the program can buy is relatively small.

Figure 4 shows FY 2006 federal expenditures for major services funded by the supportive services funding stream—access services and home and community-based long-term care services—as well as other services funded by Title III and Title VII. (Note: Federal expenditures shown differ from appropriations in part because states can transfer appropriated funds from some programs to others.¹¹)

Information and assistance — Central to the mission of the state and area agencies on aging is their role in providing information and assistance and acting as an access point for aging services programs for older people and their families. Area agencies on aging are tasked with providing convenient and direct access to information and referral services to help

FIGURE 4
Older Americans Act: Federal Expenditures for
Services Authorized by Title III and Title VII, FY 2006



older people identify, understand, and effectively use services available in their communities. According to AoA, there are about 2,100 information and referral and assistance providers across the country. An evaluation of the supportive services program found that the majority of area agencies (70 percent) provide information and assistance directly, rather than contracting with another agency. Almost half of area agencies provide toll-free telephone lines. On average, each area agency handles over 13,000 information and assistance calls annually, and most screen clients for their eligibility for home and community-based services programs.

Area agency information and assistance providers are sometimes recruited to assist in special outreach efforts. For example, they devoted considerable effort to provide older Americans information and assistance to enroll in the Medicare Part D prescription drug benefit. In FY 2006, federal Older Americans Act expenditures for information and assistance and outreach services totaled almost \$60 million, and these funds were complemented by another \$151 million from other funding sources.

Transportation services — Transportation services is the largest category of supportive services spending, accounting for over \$70 million in federal funds and serving about 47,000 people in FY 2006. An evaluation of program data for various years indicated that the program is well-targeted to vulnerable older people: about 75 percent of transportation users had at least some impairment. A 2004 survey found that about two-thirds of recipients lived alone, and three-quarters were age 75 or older. Over 80 percent of recipients said they could not drive, or had no vehicle available, and two-thirds reported that they relied on these services for at least half of their local transportation needs. Another survey found that about one-third of clients used Title III-funded transportation at least once a week. Focus groups with area agency staff, conducted as part of a supportive services program evaluation, found that transportation services were in short supply in certain areas, especially inner cities and rural areas, and that volunteers and waiting lists were being used to manage demand.

Home care services — State agencies on aging are required to devote some of their Title III funds to home care services, including homemaker, chore, and personal care services. The number of people served nationally is small: in FY 2006, about 300,000 people received Title III-funded personal care or homemaker services. ¹⁸ AoA 2004 data indicate that about three-quarters of homemaker services recipients lived alone and over two-thirds were age 75 or older; over four-fifths had an annual household income below \$15,000 (slightly more than 1.5 times the federal poverty threshold for a one-person household in 2004). ¹⁹

In FY 2006, Title III provided about \$44 million for home care services. Although the amount of funding devoted to home care is a small fraction of the amount spent under Medicaid and Medicare, the Title III program has the flexibility to serve people who may not otherwise be served under those programs. Because Older Americans Act services may be provided without

the income and asset restrictions required under Medicaid, and without the restriction that beneficiaries be in need of skilled care under Medicare, Title III funds may be used to fill gaps left by these other programs.

Evaluation — A 2006 evaluation of the supportive services program that primarily used AoA data concluded that the program serves a particularly vulnerable population. Moreover, analysis of data over a four-year period showed that for some services, such as home care and transportation, the proportion of vulnerable elderly (as measured by activity limitations and those living alone) increased. The evaluation also pointed out that agencies on aging use federal funds to leverage a substantial amount of non–Older Americans Act funds. According to this study and AoA data, for every \$1 in federal funds, state and area agencies on aging acquire more than \$2 from other funding sources.²⁰

Nutrition Services Program: Serving an At-Risk Population

A recent report indicated that about 5 million older people—over 11 percent of people age 60 and over—experience some form of food insecurity, defined as limited or uncertain availability of nutritionally adequate and safe food, or uncertain ability to acquire acceptable food. Being poor, having low education, and living alone are indicators of risk for poor nutrition. Older people lacking adequate nutrition are more likely to suffer from poor health and to have functional limitations. 22

The elderly nutrition program, the oldest and perhaps most well-known Older Americans Act service, provides meals to older people in congregate settings, such as senior centers and churches (the "congregate meals" program), and meals to frail older people in their own homes (the "homedelivered meals" program). The purposes of the program are to reduce hunger and food insecurity, promote socialization among older people, and provide meals to the homebound. The program is intended to delay the onset of adverse health conditions among older people that result from poor nutritional health or sedentary behavior.

Indirectly, the program acts as income support for many poor and near-poor older people by providing food that they would otherwise purchase (in groceries or at restaurants).²³ The program has the potential to improve older people's health by offering nutritionally adequate meals.²⁴ It also can offer nutrition counseling and education, though access to these services is limited. In FY 2006, less than 1 percent of all federal and nonfederal nutrition expenditures was devoted to counseling and education.

Funding and meals provided — The program is the largest of Older Americans Act service programs, representing almost 40 percent of the Act's total funding. In FY 2006, about 2.6 million people received 238 million meals; 59 percent of meals were served to frail older people living at home, and 41 percent were served in congregate settings. In recent years, the growth in the number of home-delivered meals has outpaced congregate meals. A number

Older people lacking adequate nutrition are more likely to suffer from poor health and to have functional limitations. of reasons account for this trend, including efforts by states to transfer funds from their congregate services allotments to home-delivered services, state initiatives to expand services to frail older people living at home, and successful leveraging of nonfederal funds for home-delivered meals services.

Data on the unmet need for nutrition services are elusive; national data on waiting lists do not exist. Some anecdotal information indicates that there are waiting lists for home-delivered meals in some areas of the country. ²⁵ In some areas, state and local funds may provide matching funds beyond the federal requirements to avoid waiting lists; in other areas, the absence of state and local funds may lead to waiting lists. Improved data collection by AoA and other organizations on unmet need among the frail population could assist in assessing program capacity and needs.

Recipients — AoA data from 2004 show that nutrition services recipients are particularly vulnerable. Almost two-thirds of congregate nutrition recipients were age 75 and older, and just over half lived alone. Over one-quarter had annual income of \$10,000 or less; 56 percent reported that the congregate meals program provided one-half or more of their daily food intake. Generally, home-delivered nutrition recipients are older and poorer than congregate recipients, and they have a high level of services needs. Almost three-quarters of recipients were age 75 and over, 61 percent lived alone, and 46 percent had an annual income of \$10,000 or less. For more than two-thirds of recipients, home-delivered meals provided at least half their daily food intake. Almost 30 percent of recipients reported needing assistance with three or more personal care activities, and almost 70 percent needed assistance with one or more other activities of daily living (ADLs), such as shopping, housework, and getting around inside the house.²⁷

Evaluation — The 2006 reauthorization legislation required the Institute of Medicine (IOM) to conduct an evidence-based evaluation of the program. To date, Congress has not provided funds for this evaluation but has stipulated that it include an evaluation of the effect of nutrition projects on the health and nutrition status of participants, prevention of hunger and food insecurity, the ability of participants to remain living independently, and a cost-benefit analysis of nutrition projects.²⁹

Family Caregiver Services: Serving Multiple Generations Through One Program

The vast majority of the elderly with long-term care needs receive care from their families and other informal, unpaid caregivers. About 7 million caregivers provide informal care to older people who need assistance with ADLs or other activities necessary to live in their own homes.³⁰ The aging of society is expected to exacerbate demands on family caregivers and increase the number of families who will be called on to provide care. Because caregiving responsibilities often lead to physical and emotional stress, and because of the increasing numbers of caregivers, many people consider the stress of caregiving to be a public health concern.

Services provided — The National Family Caregiver Support Program (NFCSP) provides grants to state agencies on aging that award funds to area agencies on aging for caregiver support.³¹ Services include information and assistance about available services, individual counseling, organization of support groups and caregiver training, respite services to provide families temporary relief from caregiving responsibilities, and supplemental services (such as home care and home adaptations) on a limited basis to complement care provided by family and other informal caregivers. In FY 2006, a little more than half of funding was spent on more costly services, such as respite care, home care or adult day care, with the remainder spent on information, access assistance, or counseling to caregivers.³²

Recipients — The number of caregivers that the program serves is small in comparison to the estimated number of caregivers of older people nationwide. In FY 2006, about 533,000 people (about 7.6 percent of all caregivers for older people) received assistance in accessing caregiver services, counseling, or caregiver training, or participated in a support group. About 103,000 people received respite care or supplemental services (about 2 percent of all caregivers).³³ Caregivers served by the program are a particularly vulnerable group. In a 2004 survey of NFCSP caregivers, over three-quarters said they had been providing care for three years or longer and almost one-quarter were age 75 or older. Over 77 percent of care recipients were age 75 and older (with over one-third age 85 or older).³⁴

Program results — A 2004 survey conducted with state officials regarding the initial years of implementation found that the program had increased the range of caregiver support that state and area agencies on aging offer. However, programs were found to be uneven across and within states. While states and area agencies have set up initiatives to coordinate the program with other home and community-based long-term care programs [such as the Medicaid Section 1915(c) waiver program], a major barrier cited was differing eligibility requirements and administrative authorities. State officials interviewed pointed to the need for better coordination of caregiver services with other long-term care services, the importance of developing methods to uniformly assess caregiver needs and provide caregiver training, and the need for additional funding for respite care services.³⁵

Disease Prevention and Health Promotion Activities: Straining to Have Broader Reach

At least 60 percent of the elderly have multiple chronic conditions,³⁶ and most health care spending is for people with chronic conditions.³⁷ Although the primary way the Older Americans Act addresses disease prevention and health promotion activities is through nutrition services, Congress has authorized specific funds for these activities as part of Title III (under subpart D). Funded at \$21 million in FY 2008, disease prevention and health promotion activities are one of the smallest Older Americans Act programs. States use funds from

The number of caregivers that the program serves is small in comparison to the estimated number of caregivers of older people nationwide. the Act to support health promotion activities at various community venues, such as senior centers and congregate nutrition sites, among others.

The types of activities that state and area agencies support with these funds vary widely. According to an assessment of eight programs completed for AoA, aging network health promotion activities include both group services, such as physical fitness and diabetes control classes and arthritis and nutrition education, as well as more individualized services, such as medical and dental screening, nutrition counseling, medication management consultation, and immunizations. Area agencies work with a wide range of public and private health and social services organizations in planning and delivering these services.³⁸

According to the AoA program assessment, the program faces a number of challenges. Although the Older Americans Act is intended to provide seed money for its programs, state and area agencies have found it particularly difficult to leverage other funding for health promotion and disease prevention activities. In addition, not being able to sustain funding is a major impediment

State and area agencies have found it particularly difficult to leverage other funding for health promotion and disease prevention activities.

to continuing programs once they are initiated.³⁹ In recent years, AoA has awarded discretionary grant funds to states and community agencies to implement evidence-based health promotion programs, such as the Chronic Disease Self-Management Program (CDSMP).⁴⁰ States are encouraging area agencies to move to evidence-based programs in their use of Title III health promotion funds. Even with these steps, increased support for health promotion and disease prevention initiatives may be needed as policymakers discuss ways to control costs for older people with chronic illnesses. A key issue is to identify effective and self-sustaining strategies.

Long-Term Care Ombudsman Program: Protecting Resident Rights

For many years, policymakers have been concerned about the quality of care in various types of residential care facilities. While most attention has been directed at nursing home quality, Congress has also been concerned about care in other residential facilities, such as assisted living facilities and board and care homes. The primary way the federal government oversees quality of care in Medicare- and Medicaid-certified nursing homes is through enforcement of a series of requirements enacted in the Omnibus Reconciliation Act 1987 (OBRA 1987) and subsequent amendments. Licensure and/or certification of residential care facilities, other than nursing homes, are the province of state government.⁴¹

A complementary way to address quality of care in nursing facilities is through protection of resident rights and consumer advocacy, which Congress established through the Older Americans Act. In 1978, Congress enacted a requirement that state agencies on aging establish an ombudsman program to advocate for, and protect the rights of, residents of long-term

care facilities. In 1987, Congress gave more prominence to the program by adding a separate authorization of appropriations for the program. And in 1992, Congress added a new title to the Act for vulnerable elder rights protection activities. Facilities that come under the purview of ombudsmen include not only nursing homes but also assisted living facilities, board and care homes, and other similar adult residential care settings.

The functions of the ombudsman program are quite broad and include investigating and resolving resident complaints; providing services to protect resident health, safety, welfare, and rights; representing the interests of residents before governmental agencies; seeking administrative and legal remedies to protect their rights; and providing consumer education.

All states, the District of Columbia and Puerto Rico, administer an ombudsman program. In most states the program is administered by state agencies on aging; in eight states, the program is contracted to entities outside state government.⁴² In 2006, there were 569 designated local ombudsman programs; the majority (61 percent) were administered by area agencies on aging.

Resident complaints — In FY 2006, the ombudsman program opened 194,000 new cases and closed 188,000 cases involving almost 307,000 complaints.⁴³ Most complaints related to resident care and rights and quality of life issues.

Funding and staff capacity — Funding for the program is rather modest considering its broad responsibilities, and the program relies on citizen volunteers to carry out its mission.⁴⁴ Some observers have raised concerns about the capacity of the program to meet its legislative mandate, given the low level of federal funding and paid staffing.

Federal funding comes primarily from two sources, Title III and Title VII, but state and local sources provide significant support as well. Of total FY 2006 expenditures (\$77.8 million), almost 60 percent came from federal funds (\$46.6 million), and the balance came from state and local sources (\$30.9 million). Although the program carries a separate authorization of funds under Title VII, most federal funding comes from Title III. The Title VII federal appropriation has grown slowly; from FY 1988 to FY 2008, funding grew by less than 1 percent a year.

In FY 2006, 1,300 paid ombudsmen (full-time equivalents) were responsible for oversight of 16,750 nursing facilities with 1.8 million beds, and 47,000 other residential care facilities with 1.1 million beds. However, most state programs could not operate effectively without volunteers who are certified by the state ombudsmen to investigate complaints—in 2005, there were 9,183 certified volunteers. Ombudsman programs rely on volunteers to maintain a presence in facilities and to investigate resident complaints.

A 1995 IOM study recommended that the staffing standard for the program be one paid full-time staff equivalent for every 2,000 beds.⁴⁷ In FY 2006, on average across all states, there was one paid full-time ombudsman for every 49 facilities and every 2,192 beds, approaching the IOM-recommended staffing

standard. However, great variation in the ratio of paid ombudsmen to beds exists. In FY 2006, only about half the states had a paid staff-bed ratio meeting the IOM recommended standard. 48

Evaluation — A number of program evaluations have taken place over the years, analyzing the value, capacity, and resources of the program. Despite repeated reports presenting evidence on the value of the program, recurring themes have pointed out that its broad mission is not supported with a corresponding level of resources. The most extensive evaluation of the program was conducted by the IOM in 1995 in response to a congressional directive in the 1992 Older Americans Act amendments.⁴⁹ The report concluded that the program "serves a vital public purpose" and has improved the long-term care system. However, it pointed out that not all residents had meaningful access to the program, the degree of implementation was uneven within and among states, and the program lacked sufficient resources to fulfill its basic mission. A more recent study by the Office of the Inspector General of the Department of Health and Human Services echoed the IOM concerns about limited staffing and resource constraints.⁵⁰ Other more recent reports have concluded with similar findings.⁵¹

Increasing responsibilities — In recent years, some state ombudsman programs have assumed responsibilities beyond complaint investigation and resolution. Increasingly, they are asked to assist residents who are making the transition from nursing homes to home or to nonfacility care in states that have begun efforts to move people out of institutions. Another area of expanding ombudsman responsibility is in investigation of complaints of recipients of home care services. Home care ombudsman programs are funded totally by states. Twelve states have developed ombudsman programs for home care recipients.⁵² With more emphasis by federal and state government on nursing home transition and home and community-based services expansion, ombudsmen may be expected to step up the intensity and scope of their activities in these areas in the future.

BEYOND THE OLDER AMERICANS ACT

Over the years, many state and area agencies have broadened their responsibilities beyond the administration of Older Americans Act funds. The activities of the aging network agencies exemplify this especially in the area of home and community-based long-term care services financed by Medicaid. In addition, many agencies administer Social Service Block Grant (SSBG) funds, the State Health Insurance Program (SHIP), Public Health Service Act funds, and state general revenue funds for myriad services for older people.

Management of Home and Community-Based Long-Term Care Services

As a result of the planning efforts undertaken by state agencies on aging during the 1970s and 1980s, it became clear to state aging administrators

that the home and community-based services system for vulnerable older people was underdeveloped and that a "continuum of care," as envisioned by the Older Americans Act, did not exist. At the same time, the federal government was giving more policy attention to "alternatives to institutional care" through various demonstration programs. Moreover, states were concerned about the growing budgets for nursing home care financed by Medicaid and wanted to place more attention on reducing—or at least controlling—the rate of increase in expenditures for institutional care. They also wanted to become more responsive to the preferences of the elderly for home and community-based services over care in institutions. This led some states to begin to focus more attention on developing home and community-based care options that could prevent or delay institutional care.

Calls by advocates and policymakers for greater access to a wider range of home and community-based care led Congress to enact the Medicaid Section 1915(c) home and community-based waiver program in 1981. The program permits the Secretary of HHS to waive

The aging infrastructure proved to be a ready-made network for waiver implementation.

certain Medicaid statutory requirements, thus allowing states to provide a wider range of home and community-based services for the elderly and other groups than are otherwise available for Medicaid reimbursement. The waiver program also allows states to control the budget for these options by targeting services to specified groups and by not providing services statewide. Implementation of waivers during the 1980s and 1990s began to change the fabric of long-term care services as states developed a broad span of services, such as care management, home care, adult day care, and respite care, to meet the needs of vulnerable populations living in the community. The program provides an opportunity to alter what some refer to as Medicaid's "institutional bias." Prior to the waiver program, care in Medicaid-financed nursing homes and other institutions was often the only option for elderly and other groups with long-term care needs and limited income and resources. (See also Cindy Shirk, "Rebalancing Long-Term Care: The Role of the Medicaid HCBS Waiver Program," National Health Policy Forum, Background Paper, March 3, 2006; available at www.nhpf.org/pdfs_bp/BP_HCBS.Waivers_03-03-06.pdf.)

Administrators and advocates for the elderly recognized that their ability to provide home and community-based services could be significantly augmented by access to Medicaid funds. Many state governments began to assign responsibility for administration and day-to-day management of the Medicaid waiver services program to state and area agencies on aging. The aging infrastructure proved to be a ready-made network for waiver implementation.

Throughout most of the aging network, administration of Medicaid waiver programs is now a core component of aging services. According to a 2004 survey, state agencies on aging in 33 states were the designated operating agencies for the Medicaid home and community-based waiver programs:

in 21 states they administered the waiver for both the elderly and younger people with disabilities, and in 12 states they administered the waiver for the elderly population only.⁵⁵ Most state agencies on aging also administer state-only funded home and community-based services for the elderly; in 32 states, state agencies on aging administer these programs for people younger than 60 who have disabilities.⁵⁶

Often, state agencies on aging have designated area agencies on aging to perform case management services and administer other waiver services. A 2006 AoA survey found that Medicaid funds are the second largest funding source administered by area agencies on aging. Thirty percent of area agency funds were from Older Americans Act sources; 26 percent from Medicaid home and community-based waivers or other Medicaid funding; and the balance from other federal, state, local, and private funds.⁵⁷

Redesigning Long-Term Care Services Delivery

Some states have redesigned their entire long-term care systems by making broad policy changes, using Medicaid funds for home and community-based services in combination with Older Americans Act and state funds. Long-term care redesign has taken various approaches including (i) restructuring state policies, administrative structures, and financing to redirect service delivery toward home and community-based services from institutional care, and (ii) integrating consumer access to services across multiple funding streams.

Some states have redesigned their systems by consolidating policy, financing, and administration into one single state agency that has control of, and is accountable for, all long-term care resources. In these cases, one agency is responsible for not only planning and development of long-term care policy, but also administration of eligibility determination, financing, regulation, service delivery, and quality for both institutional and home and community-based services. Consolidation allows state administrators to balance resources among all services and to shift funds from institutional care to home and community-based services. States that have restructured their systems include Oregon and Washington, where centralized systems are focused on a goal of eliminating any bias toward institutional care.⁵⁸

Navigating the care system, with its complex range of services and differing eligibility requirements for each program, is often a challenge for older people and their families. To improve consumer access, some states have developed integrated case management systems using single points of entry for consumers who are seeking information on long-term care services. Although single point of entry systems vary in their design, the rationale is to provide a "no wrong door" approach for consumers to access long-term care services. Some systems have personnel who conduct functional and/or financial eligibility for public home and community-based long-term care programs; some systems provide enhanced consumer information for services.

Integrated case management systems may use a wide range of programs, including the Older Americans Act, Medicaid, and state funds, to finance services for consumers. In some cases, area agencies perform functional eligibility and ongoing case management once a person is determined financially eligible for services. Single point of entry systems using area agencies operate in Indiana, Massachusetts, Ohio, Oregon, and Pennsylvania. ⁵⁹ In Washington, state officials provide the front door to services and area agencies perform ongoing case management for services once a person is determined eligible. In some states, area agencies perform a role in controlling access to nursing homes by carrying out pre-admission screening for entry into nursing homes. ⁶⁰

Abuse in domestic settings may affect hundreds of thousands of older people each year.

Prevention of Elder Abuse, Neglect, and Exploitation

Abuse, neglect, or exploitation of older adults in their own homes is a largely unrecognized, but growing, problem. Abuse in domestic settings may affect hundreds of thousands of older people each year. Although data on the full extent of the problem nationally are elusive, the best estimates indicate that between 1 and 2 million people age 65 and older have been injured, exploited, or otherwise mistreated by someone they depend on for care. ⁶¹ Generally victims are more likely to be women, and most abusers are family members. Types of abuse or neglect include self-neglect; caregiver neglect; financial exploitation; and emotional, psychological, verbal, physical, or sexual abuse. ⁶²

Each state has developed its own statutory, regulatory, and administrative authorities to address elder abuse issues. Most states have designated agencies, known as Adult Protective Services (APS) agencies, to administer services to protect adults from abuse, neglect, or exploitation. State agencies on aging in 31 states have been designated to administer APS programs. ⁶³ In most states, APS programs are considered the first responders to reports of abuse, neglect, or exploitation. ⁶⁴

According to a national survey of APS programs, reports of suspected abuse and substantiated cases have increased in recent years.⁶⁵ Increasing numbers of cases are an indicator of growing demand for services, either for investigation by state APS personnel or intervention on behalf of abused clients. Estimating incidence of abuse across the country is problematic; data showing an increase in the number of cases could be due to an increase in abuse of the elderly, or to increased awareness by the public thus generating additional reports of abuse. In addition, the number of incidents of abuse, neglect, and exploitation could be much higher, but because of problems in data collection and reporting, the full extent of incidence is not known.⁶⁶

Funding — Funding to prevent elder abuse, neglect, and exploitation comes from a variety of sources but is primarily from state and local sources. Although there are no national data on the amount of state and local funding that supports these services, one study estimated that the average state

budget for APS was \$8.6 million; the range of state funding varied widely from \$171,000 (North Dakota) to \$72 million (California).⁶⁷

To the extent that federal funding supports adult protective services, it is primarily from the SSBG (Title XX of the Social Security Act). Under the SSBG, states decide how much of their block grant funds they will spend on many different service categories. In FY 2005, of the \$2.5 billion SSBG funds for all services, states spent \$164 million on APS programs. In most states, SSBG funding far outweighs funds under the Older Americans Act. Congress has appropriated a little more than \$5 million for the Title VII elder abuse prevention program for each of the past several years.

State Health Insurance Program (SHIP)

The State Health Insurance Assistance Program (SHIP), created by the Omnibus Budget Reconciliation Act of 1990 (OBRA 1990) and administered by CMS, provides grants to states for counseling, information, assistance, and outreach programs for Medicare beneficiaries and their families regarding health insurance. The program was originally established to help older people make choices regarding Medicare supplemental insurance (Medigap). The program has expanded to provide counseling and information to beneficiaries on a wide range of Medicare and Medicaid issues, as well as Medigap, Medicare Advantage plans, long-term care insurance, and resolution of claims and billing problems. Recently, a major focus of the program has been assisting older people to make choices in prescription drug plans under Medicare Part D.

Of the 54 SHIP state grant programs, two-thirds are administered by state agencies on aging, and the remainder are administered by state insurance commissions. The SHIP program recruits and trains counselors (primarily volunteers) to conduct one-on-one counseling to Medicare beneficiaries through over 1,300 local sponsoring agencies. In 2006, over 12,000 counselors served more than 4.5 million beneficiaries through one-on-one, in-person, and telephone counseling and assistance, as well as through public education programs.

SHIP funding has grown rapidly in recent years, from \$10 million in FY 2001 to \$54 million in FY 2008, primarily as a result of the need to increase counseling efforts to beneficiaries about the Medicare discount drug card and Part D prescription drug benefit choices. In FY 2006, approximately half of the \$30 million available to state SHIP programs was distributed to area agencies on aging that provided staff and volunteer assistance to Medicare beneficiaries.⁷¹

The SHIPs and aging services network agencies coordinated their efforts during implementation of the Medicare prescription discount drug card, the Medicare Part D benefit, and the Part D low-income subsidy for those with limited income and assets. During the initial stages of implementation, many aging services network agencies reassigned staff from other

responsibilities due to overwhelming demand by beneficiaries for information and counseling on the new Medicare benefit. Over 90 percent of area agencies on aging have been involved in counseling and training efforts. During the past several years, AoA and CMS have developed a series of interagency agreements with CMS transferring \$6.4 million to AoA and national, state, and area agency on aging partners to assist in Medicare counseling efforts.⁷² As more people become eligible for Medicare, demand for counseling and assistance on Medicare issues is likely to increase.

MODERNIZING THE OLDER AMERICANS ACT: CHOICES FOR INDEPENDENCE INITIATIVE

Over the past few years, AoA has targeted the use of its discretionary funds⁷³ to launch a strategy to modernize and strengthen the aging services network. AoA has undertaken these efforts to help states and area agencies make systemic changes aimed at improving coordination and service delivery in long-term care and at reducing the risk of chronic illness among older people. AoA crafted three components as part of the initiative, referred to as Choices for Independence.

- To help consumers and their families learn about and access existing long-term care options, AoA joined CMS to award funds to states to develop Aging and Disability Resource Centers (ADRCs). ADRCs are intended to be "one-stop shop" programs at the community level that will help people make informed decisions about their service and support options. Based on a model developed in Wisconsin, ADRCs provide information and assistance to individuals needing public or private services, and individuals planning for their future long-term care needs. Resource Center programs are designed to serve as the single entry point to publicly administered long-term supports, including those funded under Medicaid, the Older Americans Act, and state revenue programs. AoA has awarded funds for 143 pilots in 43 states.
- To help people with impairments avoid nursing home placement, AoA has awarded funds to states to launch the Nursing Home Diversion modernization grant program. Through these grants, states use available home and community-based services funds to help people at the highest risk of nursing home placement remain at home and in community settings. Services are to be tailored to individual consumer needs. This program is structured to operate in concert with ADRC grants so that consumers can access a single point of entry for service planning and access. AoA has awarded funds to 12 states; federal and nonfederal commitment to the program is \$8.8 million.⁷⁶
- To complement its formula-based grant program for disease prevention and health promotion, AoA has awarded discretionary grants funds to states and community agencies to help them develop programs on evidence-based disease prevention programs. In part, these programs

have been developed using research supported by the National Institutes of Health (NIH), the Agency for Healthcare Research and Quality (AHRQ), and the Centers for Disease Control and Prevention (CDC). The aim of the projects is to implement low-cost interventions that have proven effective in reducing the risk of disease, disability, and injury among older people. Programs are focused on a number of areas, including chronic disease self-management, falls prevention, physical activity, and depression. Through this grant program, state and area agencies are developing collaborative relationships with a variety of entities such as community agencies, public health departments, universities, physicians, and health plans to provide targeted efforts in health promotion activities. In 2003, AoA awarded 12 community-level projects and expanded the program in 2006 and 2007 to over 75 pilots.⁷⁷

BROAD MISSION, LIMITED RESOURCES: CHALLENGES FOR THE FUTURE

The mission of the aging services network set out by law is expansive and is aimed at addressing many competing needs of older people across a wide spectrum of services. Despite its broad mandate and sweep of services, however, the Older Americans Act resources are relatively limited. Some have observed that funding has not kept pace with increasing demands from a growing elderly population. As a result, some programs have grown very slowly over time, or funding has not been brought to scale. Some programs' capacity depends heavily on volunteers, thereby masking any need for additional staff resources to carry out program functions. Moreover, the aging services network's decentralized planning and service model has led to variability in program implementation across states and communities.

Nevertheless, despite its funding constraints and variability in implementation, over the last 40 years, the Older Americans Act has encouraged the development and provision of multiple and varied services for older people. State and area agencies have relationships with almost 30,000 service providers offering a wide range of services across the nation. Older Americans Act funds reach limited numbers of older people, but serve the most vulnerable. Because of the mandates that state and area agencies have to coordinate services and act as advocates, they have the potential to improve access to services for older people by integrating complex programs funded by multiple financing sources.

To create an expanding service delivery system and to complement limited federal Older Americans Act dollars, state and area agencies on aging have successfully leveraged other federal funding sources. Aging services network agencies have evolved from planning and coordination entities to managers of multiple sources of funds. The ability of the infrastructure to adapt to changing demands in aging programs has led to added responsibilities

and resources for state and area agencies over time. Policymakers may want to consider other ways to build on the aging services network.

As the population ages, the sheer numbers of elderly will have significant impact on the nation's largest entitlement programs, Social Security, Medicare, and Medicaid. But this growth will also challenge the fabric of social and health-support services in communities across the nation and will affect families who care for their older family members. Aging service providers will face increasing challenges in financing and delivering a wide range of community services for vulnerable elderly, such as assisted transportation, home care, adult day care, nutrition services, elder abuse prevention, and counseling services on health and long-term care insurance issues. In the future, policymakers may need to focus on actions that will be necessary to sustain community services in the face of growing demand. These issues may become quite salient when the Older Americans Act is reviewed for reauthorization in 2011—the first year the baby boom population turns age 65.

ENDNOTES

- 1. "Greatest social need" is defined in law as those with low income and whose racial or ethnic status may heighten the need for services, as well as those who have needs related to social factors, such as those with a physical or mental disability or who experience cultural, social, or geographic isolation that restricts their ability to perform normal daily tasks or threatens their capacity to live independently. "Greatest economic need" is defined as having an income below the federal poverty level (FPL).
- 2. Some Older Americans Act service programs have specific eligibility requirements. For example, in order to receive home-delivered meals, people must be homebound. Long-term care ombudsman services are available to all residents of nursing and other residential care facilities, regardless of age. In some cases, nonelderly people may receive services; for example, people under 60 may receive nutrition services under certain circumstances, and grandparent caregivers (age 55 and older) of children may receive caregiver support services.
- 3. The exception is Title V of the Older Americans Act, which provides opportunities for low-income older people to work in subsidized employment. In order to participate, individuals must be age 55 or older and have income below 125 percent of the FPL.
- 4. National Aging Program Information Systems (NAPIS), "FY2006 U.S. Profile of OAA Programs," Administration on Aging (AoA), January 17, 2008, available at www.aoa.gov/prof/agingnet/napis/spr/2006SPR/profiles/us.pdf; and U.S. Bureau of the Census, "Population 60 Years and Over," in 2006 American Community Survey, 2007.
- 5. Older Americans Act of 1965, as amended, 45 USC 3025.
- 6. Staff of the National Association of State Units on Aging (NASUA), e-mail correspondence with author, September 11, 2007.
- 7. Frank Burns *et al.*, "2006 Survey of Area Agencies on Aging Preliminary Results," presented at the Annual Conference of the National Association of Area Agencies on Aging, August 8, 2006.
- 8. NAPIS, FY2006 U.S. Profile of OAA Programs.
- 9. Carroll L. Estes, *The Aging Enterprise: A Critical Examination of Social Policies and Services for the Aged* (San Francisco: Jossey Bass, 1979).

- 10. For example, national standards for home and community-based services do not exist. The Deficit Reduction Act of 2005 directed the Agency for Healthcare Research and Quality (AHRQ) to develop quality measures for these services, covering performance and client function and measures of client satisfaction. AHRQ, "Quality of Care Measures for Home and Community-Based Services Under Medicaid," updated May 2007; available at www.ahrq.gov/research/ltc/hcbs.htm.
- 11. Within federally prescribed limits, states are allowed to transfer funds between supportive and nutrition services and between congregate and home-delivered nutrition services. States also use funds appropriated for prevention of elder abuse, neglect, and exploitation for the long-term care ombudsman program.
- 12. Administration on Aging (AoA), "Highlights from the *Pilot Study: Second National Survey of Older Americans Act Title III Service Recipients*"; available at http://aoa.gov/about/results/Final-Highlights-2nd-national-survey.pdf [sic].
- 13. Donna J. Rabiner et al., Draft Final Report for the Evaluation of Select Consumer, Program, and System Characteristics under the Supportive Services Program (Title III-B) of the Older Americans Act, AoA, Final Report, June 2007; available at www.aoa.gov/about/results/III-B%20Final%20Report_6_26_07.pdf.
- 14. Donna J. Rabiner *et al.*, *Evaluation of the Select Consumer, Program, and System Characteristics under the Supportive Service Program* (*Title III-B*) *of the Older Americans Act*, AoA, Interim Quantitative Report, June 2006; available at www.aoa.gov/about/results/TitleIIIB_quantitative-report_6-1-06_psgFINAL.pdf.
- 15. AoA, "Highlights from the Pilot Study."
- 16. AoA, Aging Integrated Database (AGID), National Survey of OAA programs, FY2005, unpublished data.
- 17. Rabiner et al., Draft Final Report for the Evaluation of Select Consumer, Program, and System Characteristics.
- 18. AoA, "Estimated Unduplicated Count of Persons Served under Title III of the OAA, Fiscal Year: 10/01/2005 9/30/2006," 2006 State Program Reports, November 7, 2007; available at www.aoa.gov/prof/agingnet/NAPIS/SPR/2006SPR/tables/Table1.pdf.
- 19. AoA, "Highlights from the Pilot Study."
- 20. Rabiner et al., Evaluation of the Select Consumer, Program, and System Characteristics.
- 21. This is the definition used by the Economic Research Service of the U.S. Department of Agriculture. Questions used by the Current Population Survey (CPS) to measure food insecurity include: "Did you or the other adults in your household ever cut the size of your meals or skip meals because there wasn't enough money for food?" and "Did you ever lose weight because there wasn't enough money for food?" James P. Ziliak, Craig Gunderson, and Margaret Haist, *The Causes, Consequences, and Future of Senior Hunger in America*, Center for Poverty Research, University of Kentucky, and Department of Human Development and Family Studies, Iowa State University, March 2008; available at www.mowaa.org/SeniorHungerStudy.pdf.
- 22. Ziliak, Gunderson, and Haist, The Causes, Consequences, and Future of Senior Hunger in America.
- 23. Food stamp benefits may be used as contributions by older people toward the cost of meals. However, due to some administrative complications resulting from the conversion of food stamp benefits to the electronic benefit transfer (EBT) system, there is limited opportunity to use food stamps as contributions in aging nutrition programs even though participants may be food stamp—eligible.

- 24. Congregate and home-delivered meals must comply with the U.S Department of Agriculture's "Dietary Guidelines for Americans" and provide the minimum dietary intakes established by the Food and Nutrition Board of the Institute of Medicine of the National Academy of Sciences.
- 25. For example, a recent report from Kentucky cited a waiting list of 4,000 seniors for home-delivered meals. Jessica Noll, "Aging Kentuckians: a Question of Care," *KY-Post*, updated January 26, 2007; available at www.kypost.com/content/middleblue2/story.aspx?content_id=c603e9e5-0ec6-492a-ad77-7fea626ade7f.
- 26. AoA, "Highlights from the Pilot Study."
- 27. AoA, "Highlights from the Pilot Study."
- 28. The last major national evaluation was completed in 1996. Office of the Assistant Secretary for Aging, *Serving Elders at Risk: The Older Americans Act Nutrition Programs—National Evaluation of the Elderly Nutrition Program, 1993-1995*, U.S. Department of Health and Human Services, June 1996; available at www.aoa.dhhs.gov/prof/aoaprog/nutrition/program_eval/eval_report.asp.
- 29. Using funds set aside for program evaluation, AoA is in the process of conducting its own evaluation of the nutrition program that will focus on program efficiency and effectiveness and on client outcomes. "Evaluation of Title III-C Nutrition Services and Title VI Native American Nutrition, Supportive and Family Caregiver Services Programs Begun Summer 2005," AoA; available at www.aoa.gov/about/results/III-C-VI%20Evaluation%20 status%20report.htm.
- 30. William D. Spector *et al.*, "The Characteristics of Long-Term Care Users," Agency for Healthcare Research and Quality, AHRQ Publication No.00-0049, January 2001; available at www.ahrq.gov/RESEARCH/Itcusers. Activities of daily living (ADLs) refer to eating, bathing, using the toilet, dressing, walking, and getting in or out of bed. Other activities necessary for community living, or instrumental activities of daily living (IADLs), include preparing meals, managing money, shopping, performing housework, and doing laundry. Estimates based on the 1999 National Long-Term Care Survey (NLTCS), a nationally representative survey of elderly Medicare beneficiaries. (See www.nltcs.aas.duke.edu for more information on NLTCS.)
- 31. The primary groups served are caregivers of people age 60 and older, but the law allows grandparents or other individuals who are relative caregivers of children to be served under the program.
- 32. AoA, FY 2006 unpublished data.
- 33. Source of recipients is from AoA, FY 2006 unpublished data on number of caregivers caring for people age 60 and older. Percentages were derived by using the estimate of caregivers of people age 65 and older from the 1999 NLTCS. See Spector *et al.*, "The Characteristics of Long-Term Care Users."
- 34 AoA, "Highlights from the Pilot Study."
- 35. Lynn Friss Feinberg *et al.*, *The State of the States in Family Caregiver Support: A 50 State Study*, National Center on Caregiving, Family Caregiver Alliance, in collaboration with the National Conference of State Legislators, 2004; available at www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=1276.
- 36. Jennifer L. Wolff, Barbara Starfield, and Gerard Anderson, "Prevalence, Expenditures, and Complications of Multiple Chronic Conditions in the Elderly," *Archives of Internal Medicine*, 162, (November 11, 2002): p. 2269; available at http://archinte.ama-assn.org/cgi/reprint/162/20/2269.pdf.
- 37. Gerard Anderson, Chronic Conditions: Making the Case for Ongoing Care, Johns Hopkins University, November 2007; available at www.fightchronicdisease.com/news/pfcd/pr12102007.cfm.

- 38. Joshua M. Wiener *et al.*, Assessment of Title III-D of the Older Americans Act: Disease Prevention and Health Promotion Services, AoA, Final Report, January 2006; available at www.aoa.gov/about/results/Final%20Report%20DPHP%20Assessment.pdf.
- 39. Wiener et al., Assessment of Title III-D of the Older Americans Act.
- 40. AHRQ, "Preventing Disability in the Elderly with Chronic Disease," Research In Action, Issue #3, April 2002; available at www.ahrq.gov/research/elderdis.pdf. The CDSMP is a 17-hour course taught by trained lay people that teaches patients with chronic disease how to better manage their symptoms, adhere to medication regimens, and maintain functional ability.
- 41. A wide range of terms is used to describe residential care facilities that are not nursing homes. These include assisted living facilities, board and care homes, adult foster care homes, personal care homes, congregate care homes, among others. Generally, there is lack of consistency among states in the use of terminology and the requirements these facilities must meet in order to be licensed.
- 42. These states or jurisdictions are Colorado, District of Columbia, Maine, Rhode Island, Vermont, Virginia, Washington, and Wyoming.
- 43. Cases are equivalent to individuals who file complaints; complaints are the problems they identify.
- 44. Jo Harris-Wehling, Jill C. Feasley, and Carroll L. Estes, Eds., *Real People, Real Problems: An Evaluation of the Long-Term Care Ombudsman Programs of the Older Americans Act* (Washington, DC: Institute of Medicine, 1995), p. 44; available at www.nap.edu/openbook. php?isbn=NI000028.
- 45. Title III requires state and area agencies to fund the ombudsman program under a 2000 "hold harmless" requirement; that is, they are to provide at least as much support from Title III sources as they did in FY 2000. Title VII authorizes a separate appropriation.
- 46. FY 1988 was the first year the program received a separate appropriation.
- 47. Harris-Wehling, Feasley, and Estes, Real People, Real Problems.
- 48. For example, California had one paid ombudsman for every 1,472 beds; Iowa had one paid ombudsman for every 9,781 beds; and Wisconsin had one paid ombudsman for every 3,136 beds. AoA data on number of staff and beds by state. AoA, "Long-term Care Ombudsman National and State Data," updated November 9, 2007; available at www.aoa.gov/prof/aoaprog/elder_rights/ltcombudsman/national_and_state_data/2006nors/2006nors.asp.
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- 50. Office of Inspector General, "Long Term Care Ombudsman Program: Overall Capacity," U.S. Department of Health and Human Services, OEI-02-98-00351, March 1999; available at http://oig.hhs.gov/oei/reports/oei-02-98-00351.pdf.
- 51. Carroll L. Estes *et al.*, "State Long Term Care Ombudsman Programs: Factors Associated with Perceived Effectiveness," *The Gerontologist*, 44, no.1, (2004): 104–115; and Carroll Estes, "Enhancing the Performance of Long Term Care Ombudsman in New York State and California," chartbook, University of California, San Francisco, 2006.
- 52. These states are: Alaska, Idaho, Indiana, Maine, Minnesota, Ohio, Pennsylvania, Rhode Island, Vermont, Virginia, Wisconsin, and Wyoming. "Home Care Ombudsman Programs Status Report: 2007," National Association of State Units on Aging and the National Long-Term Care Ombudsman Resource Center, November 2007; available at www.ltcombudsman.org/uploads/Home_Care_Ombudsman_Programs_Status_Report_2007.pdf.

- 53. As shown in the Appendix, the Alzheimer's Disease Demonstration Grants to States authorized under Section 398 of the Public Health Service Act are administered by AoA. These grants fund home and community-based services to Alzheimer's patients and their families. In FY 2007, competitive grants were made to 38 states, primarily state agencies on aging.
- 54. The largest and best known of these demonstrations was the National Long-Term Care Channeling Demonstration begun in the early 1980s. About a dozen other demonstration projects were funded by the then-Health Care Financing Administration and the then-National Center for Health Services Research (now, the Centers for Medicare & Medicaid Services and the Agency for Healthcare Research and Quality) to test the cost effectiveness of adult day care and homemaker services compared to institutional care. Pamela Doty, "Cost-Effectiveness of Home and Community-Based Long-Term Care Services," U.S. Department of Health and Human Services, June 2000; available at http://aspe.hhs.gov/daltcp/reports/costeff.htm.
- 55. National Association of State Units on Aging (NASUA), "Four Decades of Leadership: The Dynamic Role of State Units on Aging," 2004, p. 14; available at www.nasua.org/40YearsofLeadership.pdf.
- 56. AoA estimate based on NASUA, "Four Decades of Leadership," and Martin Kitchener *et al.*, "Home and Community-based Services: State Only-Funded Programs," UCSF Center for Personal Assistance Services, February 2007, available at www.pascenter.org/state_funded.
- 57. Frank Burns et al., "2006 Survey of Area Agencies on Aging Preliminary Results."
- 58. Joshua M. Weiner et al., Redirecting Public Long-Term Care Resources, AoA, Final Report, July 2004, available at www.aoa.gov/prof/agingnet/HSSSI/Final%20Redirecting %20Case%20Studies%207-20-04.pdf; and Meridith Walters et al., A CRS Review: Home and Community-Based Services States Seek to Change the Face of Long-Term Care: Oregon, Congressional Research Service, RL32132, October 26, 2003. For other state approaches, see also Rosalie A. Kane et al., Management Approaches to Rebalancing Long-Term Care Systems: Experience in Eight States up to July 31, 2005, Centers for Medicare & Medicaid Services, May 26, 2006; executive summary available at http://hcbs.org/files/94/4668/Executive_Summary.pdf.
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- 61. Richard J. Bonnie and Robert B. Wallace, Eds., *Elder Mistreatment: Abuse, Neglect and Exploitation in an Aging America*, Panel to Review Risk and Prevalance of Elder Abuse and Neglect, Committee on National Statistics (Washington, DC: National Research Council, 2003); available at www.nap.edu/openbook.php?record_id=10406&page=R1.
- 62. National Center on Elder Abuse, "Abuse of Adults Aged 60+; 2004 Survey of Adult Protective Services," fact sheet, February 2006; available at www.ncea.aoa.gov/ncearoot/Main_Site/pdf/2-14-06%2060FACT%20SHEET.pdf.
- 63. NASUA, "Four Decades of Leadership."
- 64. Pamela B. Teaster *et al.*, *The 2004 Survey of State Adult Protective Service: Abuse of Adults 60 Years and Older*, National Center for Elder Abuse, February 2006; available at www.ncea.aoa.gov/NCEAroot/Main_Site/pdf/2-14-06%20FINAL%2060+REPORT.pdf.

- 65. APS agencies received almost 566,000 reports of suspected abuse of adults of all ages in 2003, an increase of almost 20 percent from 2000. About 192,000 reports of abuse were substantiated after investigation by APS agencies, an increase of almost 16 percent from 2000. Teaster *et al.*, The 2004 Survey of State Adult Protective Services.
- 66. Erica F. Wood, *The Availability and Utility of Interdisciplinary Data on Elder Abuse: A White Paper for the National Center on Elder Abuse*, National Center for Elder Abuse, May 2006; available at www.ncea.aoa.gov/NCEAroot/Main_Site/pdf/publication/WhitePaper060404.pdf.
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- 77. AoA, "Evidence-Based Disease Prevention Grants Program," October 31, 2007; available at www.aoa.gov/press/fact/pdf/EBDP%2011-01-07.pdf. See also, National Council on Aging, Center on Health Aging, www.healthyagingprograms.com.



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 $\mbox{CMS}-\mbox{Centers}$ for Medicare & Medicaid Services $\mbox{HHS}-\mbox{U.S.}$ Department of Health and Human Services

ACF — U.S. Administration on Children and Families

AoA — U.S. Administration on Aging

APPENDIX: Selected Long-Term Care and Health-Support Services Managed by the Aging Services Network

PROGRAM / SERVICE CATEGORY	Federal Legislative Authority, or, if applicable, Other Authority	Services Provided	Federal Administrative Agency within HHS
Home and Community-Based Long-Term Care Services	Older Americans Act (<i>Titles III and, for Native Americans</i> , <i>Title VI</i>); Medicaid home and community-based waiver programs (<i>Section 1915(c) of the Social Security Act and other Medicaid state plan options</i>); Social Services Block Grant (SSBG)	Wide range of services, including home care (for example, homemaker, home health, personal care), transportation, adult day care	AoA CMS ACF
Outreach, Information, and Assistance	Older Americans Act (Titles III and, for Native Americans, Title VI)	Connecting older people and their families to services and information about programs and services	AoA
Care Management for Home and Community-Based Long-Term Care Services	Older Americans Act (Titles III and, for Native Americans, Title VI); Medicaid home and community-based waiver programs (Section 1915(c) of the Social Security Act and other Medicaid state plan options); SSBG	Needs assessment, care planning, monitoring of services provided	AoA CMS ACF
Nutrition Services (Congregate and Home-Delivered	Older Americans Act; SSBG	Meals in congregate settings, or in a person's home; nutrition counseling and education; socialization	AoA ACF
Long-Term Care Ombudsman Program	Older Americans Act (Titles III and VII, and, for Native Americans, Title VI)	Investigation of complaints of residents of long-term care facilities (nursing home, assisted living facilities, board and care homes, similar adult care homes) and protection of rights of residents, etc.	AoA

APPENDIX: Selected Long-Term Care and Health-Support Services Managed by the Aging Services Network (continued)

PROGRAM / SERVICE CATEGORY	Federal Legislative Authority, or, if applicable, Other Authority	Services Provided	Federal Administrative Agency within HHS
Family Caregiver Services	Older Americans Act (Titles III and, for Native Americans, Title VI)	Information and assistance to caregivers about available services, individual counseling, organization of support groups and caregiver training, respite services to provide families temporary relief from caregiving responsibilities, and supplemental services (such as home care and adult day care) on a limited basis that complement care providedby family and other informal caregivers	AoA
Prevention of Elder Abuse, Neglect, and Exploitation / Adult Protective Services	Older Americans Act (Titles III and, for Native Americans, Title VI); SSBG; state and local funds	A wide array of activities to prevent abuse, including public information, and referral of complaints of abuse to law enforcement or public protective service agencies	AoA ACF
Alzheimer's Disease Grants	Public Health Service Act (Section 398)	Home and community-based services that assist Alzheimer's patients and their families such as home health care, adult day care, personal care, and institutional or home-based respite care	AoA
Disease Prevention and Health Promotion Services	Older Americans Act (Title III)	Health promotion services, such as screening for blood pressure, cholesterol, hearing, nutrition counseling, immunizations; exercise programs	AoA
State Health Insurance Program (SHIP)	Centers for Medicare & Medicaid Services (Omnibus Budget Reconciliation Act (OBRA) of 1990)	Counseling, information, assistance, and outreach programs for Medicare beneficiaries and their families regarding health insurance issues	CMS

AoA – U.S. Administration on Aging ACF - U.S.

ACF – U.S. Administration on Children and Families

 ${\it CMS-Centers}$ for Medicare & Medicaid Services ${\it HHS-U.S.}$ Department of Health and Human Services