

Chapter 7

State Programs and State and Community Service Systems That Link People to Services

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State Programs and State and Community Service Systems That Link People to Services

INTRODUCTION

One of the major policy issues in establishing a national system to link people with dementia to services is whether Congress should designate a single category of agencies to constitute the system nationwide or should mandate that each State designate the agencies that will make up the system in that State. In considering this issue, it is important to note that all States already have programs that link at least some people with dementia to services. In addition, some States and communities have a service system that links at least some people with dementia to services. This chapter discusses these State linking programs and State and community service systems.

As defined in this chapter, *linking programs are* programs that perform one or more of the functions that the Office of Technology Assessment (OTA) concludes are essential to a system to connect people with dementia to services:

- public education (i.e., providing programs and materials to help people understand dementia and the kinds of services that maybe helpful for individuals with dementia);
- information and referral (i.e., providing information about and referrals to specific services and sources of funding for services in a community);
- outreach (i.e., using any active method to identify people with dementia and caregivers who need assistance but are unlikely to respond to public education programs or to contact an information and referral source on their own); and
- case management (i.e., assessing a client's needs, developing a plan of care, arranging and coordinating services, monitoring and evaluating services, and reassessing the client's situation as the need arises).¹

Service systems are defined in this chapter as organizational entities that pool funds from several different sources and integrate the functions of various agencies that provide services in a given

geographic area. These entities are intended to create a consolidated system through which people are connected to services. An important difference between linking programs and service systems is that linking programs can be added to the service environment in a State or locality without changing the structure, function, or relationship of existing agencies or the way services are funded, whereas the creation of a consolidated service system necessarily changes the structure, functions, and relationship of existing agencies and funding procedures.

The primary purposes of this chapter are to point out the existence of State linking programs and State and community service systems and to convey a sense of their diversity. These programs and systems are a significant aspect of the environment into which any federally mandated system to link people with dementia to services would be placed. Their existence and *diversity* greatly complicate the process of designing a national linking system. If States and communities did not already have linking programs and service systems, it would be relatively easy to design a national linking system. In that case, Congress could designate a single category of agencies to constitute the system nationwide without the risk of duplicating or disrupting existing State linking programs or State and community service systems. Similarly, if existing State linking programs and State and community service systems were all alike, Congress could establish a national linking system that simply connected existing programs and service systems (although in that case, such a system probably would have been established years ago).

To design a national linking system that builds on and meshes with the diverse State linking programs and State and local service systems described in this chapter is difficult. The alternative, however, is the imposition of a system that further complicates and fragments what is already an extremely complicated and fragmented service environment. For this reason, many people, including almost all the members of the advisory panel for this OTA study, believe that Congress should mandate that each State designate

¹For OTA's analysis of why these functions are essential components of a system to link people with dementia to services, see chs. 2 and 3.

the agencies that will make up the linking system in that State. On the other hand, there are certain advantages to having Congress designate a **single** category of agencies to constitute the system nationwide, as discussed in chapter 8. The information about State linking programs and State and community **service** systems that is presented in this chapter is helpful in weighing these policy options.

The information about State linking programs and State and community service systems presented here is also relevant to another policy issue raised in the report—i.e., whether a national system to link people with dementia to services should serve only people with dementia (i.e., whether it should be dementia-specific) or whether it should serve people with other diseases and conditions as well. Most State linking programs and State and community service systems serve elderly people or elderly and disabled people. Recently, however, many States have undertaken a range of dementia-specific **initiatives**,² including dementia-specific linking programs, and a few communities have developed dementia-specific service systems.

Several State officials and other people have told OTA they are opposed to the development of dementia-specific linking programs and service systems, because, in their view, people with dementia can be served effectively by programs and systems that serve elderly and disabled people in general and because dementia-specific programs and systems contribute to the fragmentation of the service environment. On the other hand, some people, including some advocates for people with dementia and their families, believe that dementia-specific linking programs and service systems are needed because existing programs and service systems that are intended for elderly and disabled people often do not serve people with dementia effectively.

In considering the issue of whether a national linking system should be dementia-specific, it is useful to compare the dementia-specific v. general linking programs and service systems in different States and communities. In considering this issue, it is also useful to keep in mind the distinctions made in chapter 1 among the concepts *dementia-friendly*, *dementia-capable*, and *dementia-specific*. With respect to linking programs and service systems, *dementia-friendly* means that the linking program or service system is responsive to people with dementia and their caregivers. *Dementia-capable* means that the program or system is skilled in working with people with dementia and their caregivers, knowledgeable about the kinds of services that may help them, and aware of which agencies and individuals provide such services in the community. *Dementia-specific* means that the program or system serves people with dementia exclusively. As discussed in chapter 1, it is at least theoretically possible for a linking program or service system to be dementia-friendly and dementia-capable without being dementia-specific.

The information about State linking programs and State and community service systems presented in this chapter is also relevant to two other policy issues raised in the report:

1. whether agencies that constitute a national linking system should **provide** services in addition to linking their clients to services, and
2. whether the agencies that constitute the system should **allocate services or funding for services** in addition to linking their clients to services.

Some of the State linking programs and State and community service systems described in this chapter are administered by agencies that also provide services. Likewise, some of the State linking programs and all of the State and community service systems described in the chapter allocate services and/or funding for services. These State programs

²The dementia-specific initiatives undertaken by some States and localities in the past several years include: 1) establishing task forces and commissions to study the problem of Alzheimer's disease and related disorders and recommend solutions; 2) funding biomedical research on diseases that cause dementia; 3) developing caregiver support groups and caregiver education and training programs; 4) establishing regional Alzheimer's diagnostic and assessment centers; 5) sponsoring education and training programs for service providers about Alzheimer's disease, dementia, and how to care for people with dementia; 6) establishing dementia-specific in-home, adult day, and respite services; 7) modifying the eligibility requirements for publicly funded programs so that they are available to people with dementia (e.g., by adding dementia to the categories of conditions that make people eligible for services or by lowering the age requirements for certain services so that people with dementia who are under age 60 or 65 can receive them); 8) encouraging the development of special nursing home units for people with dementia; 9) establishing guidelines or regulations for nursing home special care units; 10) establishing patient registries; 11) providing cash grants to families so that they can purchase services; and 12) prohibiting private insurance policies from excluding Alzheimer's disease as a covered condition (5,14,122,333,465,5 13,576).

and State and community service systems exemplify alternate models for a national linking system.

The diversity of State linking programs and State and community service systems creates a kind of natural laboratory for comparing various approaches to linking people with dementia to services. The congressional committees that requested this assessment asked OTA to identify approaches that are being used in one State or locality and might be adapted for use in other jurisdictions. This chapter describes many such approaches.

Some of the same categories of agencies that are discussed in other chapters of this report are used by States and communities to administer their linking programs and service systems. These categories of agencies are mentioned in this chapter only if they are part of a State linking program or a State or community service system. Chapter 8 discusses area agencies on aging (AAAs), home health care agencies, community mental health centers, Alzheimer's Association chapters, the Family Survival Project, regional Alzheimer's diagnostic and assessment centers, and five other categories of agencies that link some people with dementia to services and could, at least theoretically, be designated by Congress as the basis for a national system to link people with dementia to services.

STATE LINKING PROGRAMS

Many States have linking programs that serve at least some people with dementia. The following sections describe some of these programs. The programs are categorized in terms of their emphasis on one of the four linking functions that OTA concludes are critical to an effective system to link people with dementia to services: 1) public education, 2) information and referral, 3) outreach, and 4) case management. As pointed out in the discussion, some of the programs perform more than one of these functions, but none of the programs performs all four functions. The purpose of the discussion is to convey a sense of the number and diversity of existing State linking programs and the many types of public and private agencies that are involved in implementing the programs. The discussion does not cover all State linking programs, however, and the particular programs cited are not the only good programs of their type.

Some States, notably New *York* and *California*, have numerous programs that link at least some people with dementia to services. Other States have comparatively few linking programs. The multiple linking programs in New York and California are discussed later in this chapter.

Public Education Programs



Public education programs to help people understand dementia and the kinds of services that maybe helpful for individuals with dementia may be provided by various means, including pamphlets, articles, newsletters, and other publications; posters, press releases, and public service advertising in various media; radio and television programs; audiotapes and videotapes; teaching packets and curricula; lectures, community meetings, and conferences. The primary sources of public education pertaining to dementia and services for people with dementia have been the national voluntary associations that represent people with Alzheimer's disease and other diseases that cause dementia. As described below, however, some States also have developed or paid for the development of public education programs on dementia and services for people with dementia.

In Pennsylvania, for example, the State Department of Aging has funded a variety of public education initiatives related to dementia over the past 6 years (14,650). One of these was the production, in 1984, of a television documentary on Alzheimer's disease and related disorders entitled "You Are Not Alone." Also in 1984, the department gave a grant to the Western Pennsylvania Alzheimer's Association Chapter to develop a booklet on Alzheimer's disease, "Aging and Senile Dementia-What Every Pennsylvanian Needs To know About Alzheimer's Disease and Other Types of Senile Dementia." The booklet has been distributed to individuals, support groups, hospitals, and other organizations. The Pennsylvania Department of Aging also developed a 4-part slide/audio training program for family caregivers of people with dementia. That program, which includes segments on community resources and financial and legal planning, is made available to caregivers through Alzheimer's Association chapters and AAAs. Still another public education activity of the Pennsylvania Department of Aging is the maintenance of a statewide clearinghouse that provides general infor-

mation about dementia and the kinds of services that may be needed for people with dementia.

Like Pennsylvania, several States have dementia-specific public education programs that are administered by the State's department, division, or commission on aging. In New *Hampshire*, the State Division of Elderly and Adult Services sponsors dementia-specific public education programs that provide books, articles, videotapes, service directories, workshops, and speakers for community groups (see figure 7-1) (596). In *Kansas*, the State Department on Aging has produced and distributes comprehensive resource packets on Alzheimer's, Parkinson's, and Huntington's diseases that contain general information about the disease, appropriate treatment, community services, and sources for more information (395). The cover of each book includes a toll-free number that people can call for referrals to specific service providers (see figure 7-2). In *Delaware*, the State Division of Aging funds an Alzheimer's resource center, which provides books, audiotapes, videotapes, and other educational materials about dementia and services for people with dementia (132). In *South Carolina*, the State Commission on Aging recently produced a videotape and printed educational materials on Alzheimer's disease to train AAA staff and others who work with elderly people so that they will be able to provide public education programs in their communities (78).

Many States have established a task force or committee to study the problem of Alzheimer's and other dementing diseases, and public education has been one of the primary functions of these task forces and committees. Almost all of the task forces and committees have issued reports that provide information about dementia and services for people with dementia.³ Members of the task forces and committees also speak about these topics to community groups. In addition, most of the task forces and committees have sponsored public meetings that serve as educational forums as well as giving family caregivers and others an opportunity to testify about the problems they face in caring for a person with dementia.

Some States, *Ohio* and *Michigan* among them, have developed or paid for the development of training manuals for family caregivers of people

with dementia (528,618). Other States, including *Georgia* and *Nevada*, have funded or otherwise supported the efforts of Alzheimer's Association chapters to develop and disseminate public education materials and programs (260,576).

In *Alaska*, the Older Alaskans Commission has given grants since 1984 to the Alzheimer's Disease Family Support Group (a private organization in Anchorage) to provide statewide public education programs about dementia and services for people with dementia (282,576). Alaska has many remote communities, so the Alzheimer's Disease Family Support Group has used both teleconferences and printed materials to provide information about dementia to caregivers, providers, and others.

Information and Referral Programs



Information about and referrals to specific services and sources of funding for services in a community can be provided by telephone or in person. Most of the State information and referral programs are telephone programs. Some of the programs are intended to serve elderly people or people of all ages, and others are specifically intended to serve people with dementia.

A 1988 survey by the National Association of State Units on Aging found that 32 States had a statewide toll-free telephone information and referral program for elderly people or people of all ages: 18 of the 32 programs were for elderly people, and the remaining 14 were for people of all ages (577). The extent to which existing information and referral programs for elderly people or people of all ages meet the needs of people with dementia and their caregivers undoubtedly varies, but anecdotal reports suggest that many of the existing programs fall short in this regard. Such reports, in fact, were one impetus for this OTA study.

Some States have tried to enhance the capability of their information and referral programs to serve people with dementia by requiring special training for the staff of the programs and by developing dementia-related materials for use by the programs. In *Illinois*, for example, the Governor's Task Force on Alzheimer's Disease has developed a special information packet for people who call the State's

³For a list of the reports published by State task forces and committees on Alzheimer's disease and related disorders, see app. C.

Figure 7-1—A Brochure Publicizing the Public Education and Other Services of the New Hampshire Division of Elderly and Adult Services

**SERVICES OF THE
NEW HAMPSHIRE DIVISION OF
ELDERLY & ADULT SERVICES**

Call or write the Coordinator for
Alzheimer's Services at (603) 271-4687
for:

- information and referral for families
- books, articles, and videotapes on loan
- guides to services in eleven N.H. regions
- information about specific family support groups
- bibliography on ADRD
- community education speakers
- training workshops
- consultation to service programs
- respite care services

A. D. R. D.



New Hampshire Division of Elderly & Adult Services

*A public information service of
The New Hampshire Division*

of Elderly & Adult Services

**Department of Health
and Human Services**

*6 Hazen Drive
Concord, NH 03301
(603) 271-4667*

1988

Figure 7-2—A Resource Packet on Parkinson's Disease Produced and Distributed by the Kansas Department on Aging

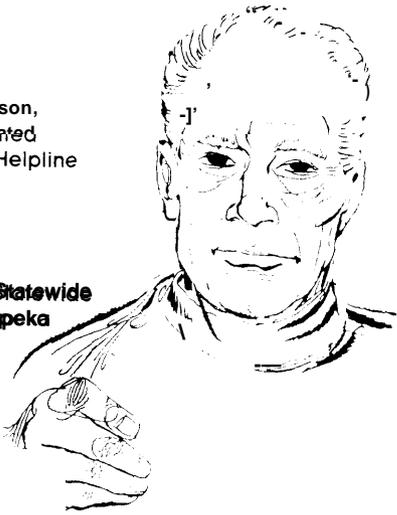
Parkinson's Disease

GRANDPA HAS A DISEASE
THAT MAKES HIM FORGET . . .
FIND OUT WHY.

For information on
Alzheimers, Parkinson,
Huntingtons & Related
Disorders call the Helpline



1-800 -432-3535 Statewide
296-4986 Topeka



KANSAS DEPARTMENT ON AGING

SOURCE: Kansas Department on Aging, *Resource Packet: Parkinson's Disease*, Topeka, KS, June 1988.

telephone information and referral program for seniors about services for a person with dementia (345).

As discussed below, by 1989, at least 14 States had established a statewide telephone information and referral program specifically for people with dementia. Many of the dementia-specific information and referral programs exist in addition to a State's information and referral program for elderly people or for people of all ages. In *Massachusetts*, for example, the State's Office of Elder Affairs has a statewide Alzheimer's telephone information and

referral program that it has operated since 1985 (121). The State's Office of Elderly Affairs also has a separate telephone information and referral program for elderly people.

Since 1988, *Connecticut* has funded a statewide Alzheimer's telephone information and referral program through Info-Line, a United Way program (143). Before 1988, Info-Line responded to calls about services for people with dementia, but the new program provides special training about dementia and about services for people with dementia for Info-Line staff members who handle those calls.

Texas has an Alzheimer's telephone information and referral program that is operated by the State Department of Health. In 1988, the Texas Legislature mandated the development of a computerized information and referral program for people with dementia, and the Department of Health is developing that program.

Pennsylvania, *New Hampshire*, *Kansas*, and *Delaware* provide dementia-specific telephone information and referral programs through the same agencies that administer their public education programs (see previous section). *New Jersey* funds a statewide dementia-specific information and referral program through its two Alzheimer's diagnostic and assessment centers, and *Florida* funds information and referrals for people with dementia through its four memory disorders clinics.⁴ *New York* and *California* also have statewide dementia-specific information and referral programs that are discussed in a later section of this chapter.

North Carolina funds a statewide telephone information and referral program for people with Alzheimer's disease and other dementias through the Duke University Medical Center's Family Support program (290). Two social workers and a secretary respond to approximately 200 calls a month and provide information about dementia, referrals to community service providers, and telephone counseling. The State-funded program also provides public education, professional and caregiver training, and caregiver support groups.

Wisconsin funds a statewide information and referral program for people with dementia and their families through the Alzheimer's Information and

⁴New Jersey's centers and Florida's memory disorder clinics are discussed along with other State regional Alzheimer's diagnostic and assessment centers in ch. 8.

Training Center, which is operated by the Alzheimer's Association Chapter of Southeastern Wisconsin (263,410).⁵The center maintains a computerized database of all the dementia-related services in the State, organized by county. Callers, who include family caregivers and health care and social service professionals who work with dementia patients and their families, can access the information and referral program through a toll-free number. In addition to providing information and referrals, the center develops and distributes educational materials and provides training for professionals and caregivers.

The *Missouri* Division of Aging has both a statewide telephone information and referral program for elderly people and a statewide telephone information and referral program for people with Alzheimer's disease and their caregivers (219). Those programs are described in box 7-A. Anecdotal reports suggest that some caregivers of people with dementia prefer to call a dementia-specific information and referral program. Other caregivers may be reluctant to call a dementia-specific program because they are ashamed of their relative's cognitive impairment and prefer to call an information and referral program that serves elderly people in general. Still other caregivers may not consider calling a dementia-specific program because they do not think of the individual as a "person with dementia;" probably this is especially likely if the individual has physical impairments in addition to dementia. The Missouri system with its two telephone numbers, advertised separately but answered by the same staff (all of whom have received training about dementia and services for people with dementia) is a creative way of providing information and referrals for caregivers who have any of the three perspectives. The close working relationship between the State programs and the Alzheimer's Association chapters is another positive feature of the Missouri system.

In addition to maintaining telephone information and referral programs, some States have published resource directories that list available services for people with dementia. In 1988, for example, New Jersey published the third edition of its resource directory, *Alzheimer's Disease: A New Jersey Directory of Services for Family Caregivers and Health and Human Service Providers* (601). Some States publish directories of services for elderly

people, and these directories may also be helpful for people with dementia (374).

In 1989, the Dementia Subcommittee of *Michigan's* Chronic Disease Advisory Committee proposed the establishment of a statewide network of agencies that would provide information and referrals and a variety of other services for people with dementia and their caregivers (528). One component of the subcommittee's proposal is the designation of one agency in each community as a "center for information on dementia." According to the proposal, these centers would be the focal points for information about dementia in the community. They would be the local repository for printed and audiovisual materials about dementia, lists of speakers, and other public education materials. They also "would assist families in locating and obtaining appropriate services" (528).

The Dementia Subcommittee anticipates that organizations, such as Alzheimer's Association chapters, other voluntary organizations, AAAs, local health departments, and Community Mental Health Boards will apply to be designated as centers for information on dementia (528). The subcommittee proposes that it, along with several other groups, should select one organization to be the dementia information center in each community. The selection would be based on the applying organizations' relative knowledge about dementia and services for people with dementia, their relative ability to maintain an up-to-date directory of available services, and evidence of support from other community agencies for their selection.

The working group that developed the subcommittee's proposal believed that although the centers for information on dementia would not receive any State funds, local organizations would nevertheless apply to be designated as centers because of the recognition and authority such designation would bring them (1). The subcommittee's proposal suggests that if no agency or organization applies from a particular geographic area, the State could solicit applications from agencies and organizations in that area or ask a designated center in a nearby community to expand its catchment area (528).

The working group that developed the subcommittee's proposal debated the advisability of having the local centers for information on dementia

⁵Wisconsin's Alzheimer's Information and Training Center is described at greater length in box 8-G in ch. 8.

Box 7-A—Missouri's Information and Referral Programs for Elderly People and for People With Alzheimer's Disease

The Missouri Division of Aging has both a statewide telephone information and referral program for elderly people and a statewide telephone information and referral program for people with Alzheimer's disease and their caregivers. The information and referral program for elderly people gets about 10,000 calls a year. The Alzheimer's "Helpline" was initiated in 1988, and received 100 calls the first day. Subsequently, the number of calls decreased somewhat.

Calls to both of these Missouri information and referral programs are answered by the same staff. All staff members at these programs receive 4 to 5 hours of training by the Missouri Alzheimer's Association Coalition. The training includes an overview of Alzheimer's disease, including its causes and behavioral manifestations and its impact on family caregivers; reasons why caregivers of people with Alzheimer's disease might call the information and referral programs; the kinds of questions these caregivers might ask potentially helpful services for people with Alzheimer's disease; and procedures for handling emergencies (e.g., the patient is lost or uncontrollably agitated or the caregiver is sick or suicidal).

When a person calls either of the Missouri information and referral programs about an individual with dementia, the program gives the person information about services and a referral to the Alzheimer's Association chapter or support group nearest the person's home (Missouri now has Alzheimer's Association chapters covering all counties in the State). The program also sends a followup letter to the Alzheimer's Association chapter to which the caller is referred unless the caller requests that no followup be made.

The general elderly and Alzheimer's-specific telephone information and referral programs of the Missouri Division of Aging both use a common computerized database of services. The database can be accessed at the Missouri Division of Aging's central office. Since it can also be accessed through computer terminals in about 100 of the division's local offices, it is available to case managers who work in those offices. The Missouri Division of Aging hopes that it will be possible in the near future to generate by computer the followup letters to Alzheimer's Association chapters about callers who have been referred to them.

SOURCES: B.L. Forbis principal assistant to the director, Division of Aging, Missouri Department of Social Services, Jefferson City, MO, personal communication, Dec. 6, 1988, Apr. 5, 1989, and June 14, 1989; K. Higley, **executive** director, St. Louis Alzheimer's Association Chapter, St. Louis, MO, letter to the Office of Technology Assessment, U.S. Congress, Washington, DC, Apr. 14, 1989.

provide 'gatekeeper-type' outreach⁶ and case management in addition to public education and information and referral (1). Including case management and outreach as functions of the proposed centers would have made it difficult for some of the local organizations that were already providing public education and information and referrals for people with dementia and their caregivers to qualify as centers, however, and the subcommittee's final proposal did not require the centers to provide these functions (or even discuss the functions). The final proposal does recommend that the centers be able to contact service providers on behalf of dementia patients and their families, if necessary, and to follow-up to ensure that patients and families obtain needed services.

Michigan's proposed centers for information on dementia would be required to work closely with other individuals, groups, and agencies in the community, including physicians, voluntary associ-

ations, and public and private agencies that provide services for-people with dementia (528). The local centers would also be required to work closely with the two other components of the proposed statewide network of agencies: regional centers and tertiary centers. According to the proposal, the regional centers would provide diagnosis, multidimensional assessment, care planning, "short-term care management," and counseling for families. The tertiary centers would provide specialized diagnostic and assessment services for dementia patients with atypical or complicated symptoms and would conduct research, education, training, and autopsy programs.

It is interesting to note that the Dementia Subcommittee's proposal places the information and referral functions in the local centers for information on dementia and places the case management functions in the regional centers (528). This is opposite to suggestions OTA has heard from other people who

⁶The following section discusses gatekeeper programs,

believe that although information and referral can be provided effectively on a regional or statewide basis, case management must be provided by local agencies (374,595).

Outreach Programs



Outreach, as noted earlier, means using an active method to identify people with dementia and caregivers who need assistance but are unlikely to respond to public education programs or to contact an information and referral program on their own.⁷ The outreach programs that most closely match the needs of isolated people with dementia and their caregivers are “gatekeeper programs” that make use of the observations of individuals who interact with many people in the course of their regular activities—e. g., utility meter readers, mail carriers, apartment managers, police, pharmacists, grocers, and delivery persons. Gatekeeper programs train such individuals to identify isolated elderly people who may need assistance and to notify a central agency. The central agency then contacts the people, evaluates their needs, and refers them to services (97,320,456,688).

The first gatekeeper program in the United States was established in 1978 by a community mental health center in Spokane, Washington.⁸ Since then, gatekeeper programs have been established in many other jurisdictions, often as joint initiatives of the State department, division, or commission on aging, AAAs, and utility companies (320). Although these programs are not dementia-specific, they frequently identify and refer isolated people with dementia (97,320,456,685).

Illinois has a statewide system of gatekeeper programs that are administered by the Illinois Department on Aging and local AAAs in conjunction with several utility companies and rural cooperatives. With the addition in 1989 of Commonwealth Edison in northern Illinois, the gatekeeper programs now cover the whole State (148). The AAAs provide training for the utility workers who are the gatekeepers and determine which local agency should receive and respond to referrals from the gatekeepers. In some localities, the calls are handled by the AAA, whereas in other localities, they are handled by the

case management agencies that administer Illinois’ Community Care Program, a statewide long-term care program that is discussed later in this chapter.

Case Management Programs



Case management, as noted earlier, is a process that includes five core functions: 1) assessing a client’s needs, 2) planning care, 3) arranging and coordinating services, 4) monitoring the services that are provided, and 5) reassessing the client’s situation as the need arises.

All States have at least one program that provides case management for elderly people, although the number of people who receive case management through some of the State programs is very small (354). Some States provide case management through an independent case management program; some States provide case management as a component of a program that also allocates services or funding for services; and some States provide case management through several different programs. The number of people with dementia who receive case management through State programs is not known.

As noted in chapters 1 and 3, the implementation of case management functions varies depending on the type of agency that provides the case management, the other functions of that agency, and other factors. In State agencies that allocate services or funding for services, case management provided in conjunction with the administration of those benefits sometimes consists primarily of administrative tasks such as determining a client’s eligibility for services and funding, authorizing the services and funding, and monitoring and accounting for them. Many of the case managers who work for such agencies perceive themselves not just as administrative agents but as professional helpers who assist clients in defining their service needs and locating and arranging appropriate services (47). OTA has no reason to dispute these case managers’ perception that the case management they provide has both administrative and clinical/advocacy components, although case management in such agencies is undoubtedly more likely than case management provided by an

⁷As noted in chs. 1 and 3, some programs that are called “outreach” programs by the agencies that provide them—e. g., lectures given by agency staff to senior citizens or other community groups—are considered public education programs in this report.

⁸The Spokane gatekeeper program is discussed in box 8-C inch. 8.

independent case management program to consist primarily of administrative tasks.

A 1987 survey of the 50 States and the District of Columbia conducted by the Intergovernmental Health Policy Project found that States were paying for case management for elderly people with funds from many different sources (353,354). Some States were paying for case management as an optional Medicaid benefit (allowed since 1986) or through a Medicaid 2176 waiver (both these funding sources are discussed below); 33 States were paying for case management with Older Americans Act funds; 32 States were paying for case management with State general funds; and 23 States were paying for case management with Social Service Block Grant funds.

The case management that States were paying for was administered at the State level by different agencies in different States and by several agencies in some States. These agencies include the State department, division, or office on aging, the State Medicaid agency, and the State department of health, social services, or human services (353,354). At the local level, the case management that States were paying for was provided to clients by a variety of agencies, including local offices of various State and county departments, city government agencies, AAAs, and many types of private agencies. Many States reported providing case management through several different local agencies. A few States reported contracting with individual nurses to provide case management.

As of October 1987, 15 States were paying for case management as an optional Medicaid benefit (819). OTA is not aware of any data on the number of people with dementia who receive case management that is paid for as an optional State Medicaid benefit, but some people with dementia probably do receive this benefit. To be eligible for case management as a Medicaid benefit, one must meet the State's Medicaid financial eligibility criteria, and the allowable levels of income and assets for Medicaid eligibility are low in some States and very low in other States.⁹

The Medicaid 2176 waiver program was enacted by Congress in 1981 to allow States to apply for waivers of Medicaid regulations so they could provide a coordinated package of home and community-based services for individuals who otherwise would be at risk of nursing home placement or who are already in an institution (819). A State with a Medicaid 2176 waiver:

- may use Medicaid funds to pay for services that are not ordinarily covered by Medicaid;
- may use Medicaid funds to pay for services for some Medicaid beneficiaries and not others, so that benefits can be targeted; and
- may use a higher income standard to determine individuals' 'eligibility for services under the 2176 waiver program than is used to determine eligibility for other Medicaid services.

As of February 1988, there were 45 Medicaid 2176 waiver programs serving elderly and disabled people in 36 States (some States had more than one such program) (819). Thirty-six of these 2176 waiver programs provided case management, and many of the waiver programs provided services that are sometimes needed for people with dementia, including homemaker services (28 programs), personal care (20 programs), adult day care (30 programs), and respite care (28 programs). In fiscal year 1986, Medicaid 2176 waiver programs across the country served a total of 78,000 elderly and disabled people (819).

Ohio's Pre-Admission Screening System Providing Options and Resources Today (PASSPORT) program has a Medicaid 2176 waiver to provide case management and an expanded package of services for people who are eligible for Medicaid-covered nursing home care but choose to remain at home (622). At the State level, the PASSPORT program is administered by the Ohio Department of Aging. At the local level, it is most often administered by AAAs. Case managers in the AAAs and other local agencies that administer the program provide an assessment and a service plan for each client, arrange the necessary services for the client, and monitor the service providers and the client on a continuing basis. The local agencies also contract

⁹As of 1987, allowable monthly income levels for Medicaid eligibility ranged from \$253 in North Carolina to \$580 in California and \$652 in Alaska. Allowable assets levels ranged from \$1,500 to \$1,800 (826). Some States also allow Medicaid eligibility for people who are "medically needy" —i.e., they have medical expenses that reduce their incomes to Medicaid eligibility levels. For further information on this topic, the interested reader is referred to a 1987 publication of the Congressional Research Service, prepared by the National Governors' Association, *Medicaid Eligibility for the Elderly in Need of Long-Term Care* (826).

with other community agencies to provide services for PASSPORT clients (623).

As of September 1989, the PASSPORT program was in effect in only 12 Ohio counties and PASSPORT services were available only to people with income and assets low enough to qualify for Medicaid in Ohio. Ohio has applied to the Federal Government for a waiver to expand the PASSPORT program statewide and to make the program's services available to people with incomes up to \$718 per month. People with monthly incomes above that amount would also be able to receive services through the program if they used their own income above \$718 per month to pay for services (622).

Medicaid 2176 waiver programs are undoubtedly a valuable resource in linking some people with dementia to services. On the other hand, many people with dementia (like many other elderly and disabled people) are not eligible for Medicaid 2176 waiver programs because they do not meet the eligibility requirements for Medicaid-funded nursing home care (e.g., requirements with respect to their medical condition, functional impairments, and financial resources). Two 1985 studies of Medicaid 2176 waiver programs that serve elderly and disabled people found that only 5 percent of the waiver program participants had a primary diagnosis of a mental disorder—a category that included cognitive impairments and senility (131,446). It is likely, however, that Medicaid 2176 waiver programs serve some people who are demented but who do not have a primary diagnosis of a dementing disorder.

Existing Medicaid 2176 waiver programs such as the PASSPORT program in Ohio would not have the capacity to serve all people with Alzheimer's disease and other dementing disorders even if the waiver programs' eligibility criteria were changed to allow them to do so. In 1987, in commenting on Ohio's PASSPORT program, the Ohio Department on Aging noted, for example, "even if the entire caseloads of the four waiver sites were reserved for Alzheimer's patients, the available resources could respond to less than 1 percent of the need of Ohio's Alzheimer's population" (621).

Pennsylvania's Long-Term Care Assessment and Management Program (LAMP) is similar in many ways to Ohio's PASSPORT program, but it does not have a Medicaid 2176 waiver and is paid for solely with State funds (354). Pennsylvania's LAMP program offers case management and a range of

services to elderly people who are eligible for Medicaid-funded nursing home care but choose to remain at home. The program is jointly administered by Pennsylvania's Departments of Aging and Public Welfare. The State of Pennsylvania contracts with local agencies to be designated as LAMP sites and to provide assessment and ongoing case management. For each client, the local LAMP agencies provide a comprehensive assessment, develop a plan of care, and arrange and monitor services. The LAMP sites contract with community agencies to provide other services. In general, the cost of services provided to LAMP clients must be less than 45 percent of the cost of nursing home care. State lottery funds are used to pay for services for LAMP clients when no other source of funding is available (505,562,651). A small study based on a probability sample of 27 people served by Pennsylvania's LAMP program in 1987 found that half had moderate or severe dementia (505).

Any local agency can be designated as a LAMP site, as long as it is capable of carrying out the required functions and is not a service provider. LAMP sites determine people's eligibility for nursing home care, so in selecting LAMP sites, Pennsylvania must evaluate whether a potential LAMP agency has any potential conflict of interest in performing that function. In 1987, all but one of the local LAMP agencies were AAAs, and in 1988, all the LAMP agencies were AAAs (652).

States With Numerous Linking Programs

Certain States, notably *New York* and *California*, have numerous State programs that link at least some people with dementia to services. The major State linking programs in *New York* and *California* are described in the following sections. The programs vary in terms of the kind of help they provide and the people they serve. Some of the linking programs in each State are dementia-specific, and others are not.

In addition to programs that are funded and administered by the State, there are many other public and private programs and agencies in each of the States that link people with dementia to services. Some of these programs are listed at the end of each section to give a sense of the large number and the different types of linking programs in the State. It should be noted that although there are some positive consequences of having numerous linking

programs in the same State, a multiplicity of linking programs may not always be a good thing, since the linking programs themselves can become confusing and add to the complexity and fragmentation of the already complicated service environment.

New York State% Linking Programs

To OTA's knowledge, New *York State* has eight State programs that link at least some people with dementia to services. New York State's Department of Health administers two dementia-specific programs that link people to services:

- the *Alzheimer's Disease Community Services Program*, and
- a program of *Alzheimer's Disease Assistance Centers*.

New York's Alzheimer's Disease Community Services Program, which began in 1986, provides grants to eight Alzheimer's Association chapters to furnish public education and information and referral, in addition to training and support for caregivers of people with Alzheimer's disease and other dementias. Since 1988, the State has also funded eight Alzheimer's Disease Assistance Centers that provide diagnosis, assessment, and ongoing case management for people with Alzheimer's disease and other dementias. Seven of the Alzheimer's Disease Assistance Centers are located in medical centers of the State University of New York, and one is in a nursing home. Each Alzheimer's Disease Assistance Center has an information clearinghouse that provides information about dementia and services for people with dementia. Telephone information and referrals are not the centers' primary function, but they do respond to requests from anyone for referrals to services (608,248).

New York State's eight Alzheimer's Disease Community Services Programs and eight Alzheimer's Disease Assistance Centers are situated throughout the State (see figure 7-3), and anyone from any part of the State can use any of the programs or centers. New York State's Department of Health considers that some areas of the State are not adequately covered by the existing programs and centers, however, and plans are under way to fund additional programs and centers (248).

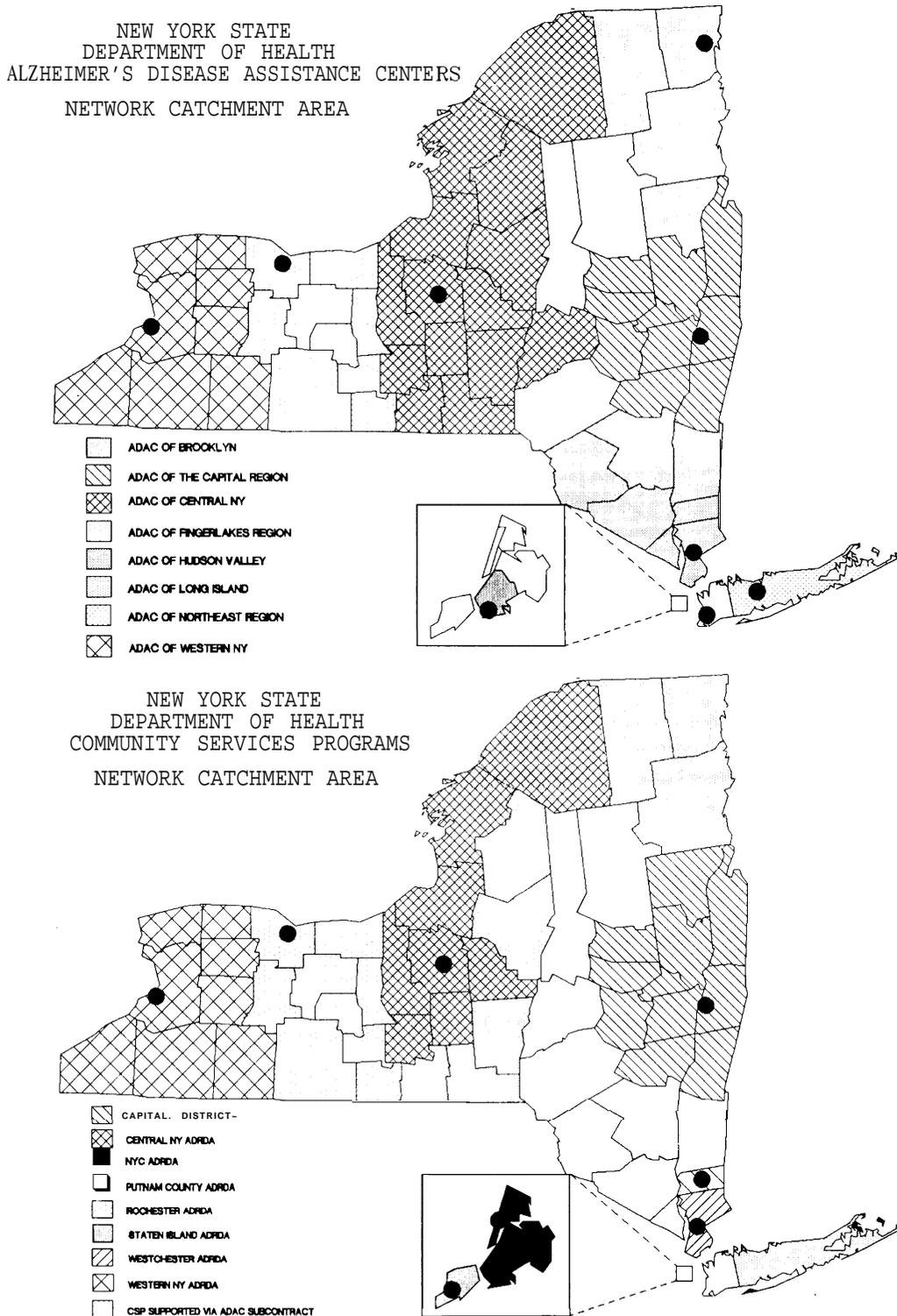
In addition to these two dementia-specific programs, New York also has at least six other State programs that are not dementia-specific but nevertheless link some people with dementia to services.

One of the programs is the *Nursing Home Without Walls Program* (354,472). This program, begun in 1977, has had a Medicaid 2176 waiver since 1983. The Nursing Home Without Walls Program currently provides case management and in-home services for people of all ages who are sufficiently impaired to be eligible for Medicaid-funded nursing home care but choose to remain at home. At the State level, the program is administered by New York State's Department of Social Services, Division of Medical Assistance. At the local level, the program is administered by a variety of community agencies. As of 1986, the Nursing Home Without Walls program existed in 51 of New York State's 62 counties; the 95 local agencies that administered the program included home health agencies (46 percent), nursing homes (35 percent), and hospitals (19 percent). Expenditures for Nursing Home Without Walls clients are capped at 75 percent of the average annual cost of nursing home care in the State, but a 1987 State law raised the cap for people with Alzheimer's disease to 100 percent of the cost of nursing home care (354).

In addition to the Nursing Home Without Walls Program, New York State's Department of Social Services, Division of Medical Assistance, has another program that coordinates in-home and community services in order to maintain people at home who otherwise might be admitted to a nursing home. This program, the *Community Alternative Systems Agency (CASA)* program, has designated a single agency in certain communities to be the local entry point for assessment and ongoing case management for people who are eligible for Medicaid-funded in-home services. Most CASAs are county departments of social services or other county government agencies (122,354).

New York State's Medicaid program, like that in some other States, pays for case management (354). People can be eligible for Medicaid-funded case management without being so impaired that they are eligible for Medicaid-funded nursing home care, but they do have to meet Medicaid's financial eligibility criteria. As of 1987, individuals living in the community had to have an income below \$432 per month to be eligible for Medicaid benefits, including case management. People with higher incomes were eligible only if their medical expenses reduced their income to the Medicaid eligibility levels (i.e., they were "medically needy").

Figure 7-3-Areas of New York Served by the State's Alzheimer's Disease Assistance Centers and Alzheimer's Disease Community Services Programs



SOURCE: New York State Department of Health, Office of Public Health, Alzheimer's Disease and Other Dementias Program, January 1990.

New York State's Department of Social Services, Division of Adult Services, pays for case management and in-home services for adults with incomes that exceed Medicaid eligibility levels (in 1987, up to 150 percent of the poverty level). This program is funded with Federal Social Services Block Grant monies and administered at the local level by county departments of social services (354).

New York State's Office on Aging funds two statewide programs that are administered at the local level by AAAs and provide case management and other in-home and community services for people who are over age 60 and not eligible for Medicaid:

- the *Community Services for the Elderly (CSE)* program, and
- the *Expanded In-Home Services for the Elderly (EISEP)* program (354).¹⁰

AAAs in New York State also provide information and referrals, and some provide case management, using Federal Older Americans Act funds (354).

In addition to State linking programs, New York has many other public and private programs and agencies that link people with dementia to services. They include the New York City Alzheimer's Resource Center,¹¹ Alzheimer's Association chapters, community health centers, community mental health centers, hospitals, county and city government agencies, private social service and family service agencies, home health agencies, and adult day centers.

Two federally funded programs in New York State also link people with dementia to services. One is the Monroe County Long-Term Care Program in Rochester, New York, which in 1988 was designated as one of eight demonstration sites for the Medicare Alzheimer's Disease Demonstration. Like each of the other Alzheimer's demonstration sites, the Monroe County Long-Term Care Program will provide information and referrals, case management, and in-home and community services for several hundred Alzheimer's patients over a 3-year period beginning in late 1989 (504). In addition, New York State has 2 of the 15 Alzheimer's Disease Research Centers funded by the National Institute on

Aging; the centers are located at Mt. Sinai School of Medicine and Columbia University, both in New York City. The centers are primarily biomedical research facilities, but they also provide educational programs for the public and information and referrals for people who are involved in their clinical research programs.

California's Linking Programs

To OTA's knowledge, *California* has seven State programs that link at least some people with dementia to services. Three of the programs serve only or primarily people with dementia. First, California's Department of Health Services funds a program of nine *Alzheimer's Disease Diagnostic and Treatment Centers* (225,335).¹² The nine centers provide diagnosis, assessment, and medical treatment for people with Alzheimer's and related dementias, conduct biomedical and clinical research on dementia, and train service providers. The centers provide educational programs for community groups and information and referrals for patients and family caregivers. One of the centers provides long-term case management. Three of the centers are located on university campuses; two are at VA medical centers; and the others are at a psychiatric hospital, a rehabilitation hospital, a community hospital, and a senior center.

Second, California's Department of Aging funds a program of *Alzheimer's Day Care Resource Centers* that provide public education, information and referrals, and professional and caregiver education and training, as well as adult day care and respite care for people with dementia (5,460,714). As of 1989, there were 26 Alzheimer's Day Care Resource Centers throughout California, administered by a variety of public and private health care and social service agencies. In 1990, 10 more centers will be added, bringing the total to 36 centers.

Third, California's Department of Mental Health funds a network of *regional resource centers for the families and caregivers of brain-impaired adults*. The centers, which are modeled after Family Survival Project in San Francisco, provide public education, information and referrals, case coordination, and other services for the families and other

¹⁰As of 1987, the EISEP program served people with incomes between 150 and 250 percent of the poverty level (354).

¹¹The New York City Alzheimer's Resource Center is discussed in box 8-A in ch. 8.

¹²For additional information on California's Alzheimer's Disease Diagnostic and Treatment Centers, see the Section on regional Alzheimer's diagnostic and assessment centers in ch. 8.

caregivers of brain-impaired adults, the majority of whom have dementia.¹³ As of 1989, there were 11 regional resource centers (including Family Survival Project) located throughout California (see figure 7-4). Four of the centers are administered by hospitals or rehabilitation centers; others are administered by an AAA, a Catholic Charities agency, and other health care and social service agencies. Most of the centers serve several counties. Eight centers have toll-free telephone numbers, and several have family consultants who are available to people in rural parts of the centers' catchment areas (199,200,405).

The State of California has designated Family Survival Project to serve not only as the Bay Area Regional Resource Center but also as the Statewide Resources Consultant. In the latter capacity, Family Survival Project maintains an information clearinghouse on dementia and other conditions that cause brain impairment and publishes a newsletter, fact sheets, brochures, directories, and research reports about services for brain-impaired adults and their caregivers (199,200,405). It also refers callers to the regional resource center designated to serve their geographic area and responds to requests for information from callers outside the State.

Since its inception as a task force of families and community leaders in 1976, Family Survival Project has lobbied, often successfully, for improved services for people with dementia, other brain-impaired adults, and their families. It maintains detailed records of services that are needed but not available to its clients. To a greater extent than any of the other agencies OTA studied in the course of this assessment, Family Survival Project uses its client records to point out to government officials and others the need for specific services. The development of California's statewide network of regional resource centers, completed in 1988, allows Family Survival Project to compile information about patients, caregivers, service use, costs, and unmet service needs for the State as a whole.

In addition to these three dementia-specific programs, California has four other State programs that are not dementia-specific but nevertheless link at least some people with dementia to services. The *Multipurpose Senior Services Program (MSSP)*,

which began in 1980, provides case management for elderly people who meet Medi-Cal (California's Medicaid program) eligibility requirements for nursing home care but can be maintained at home with services (101,354,534). MSSP pays for in-home and other community services for its clients if the services cannot be funded through any other source. Total expenditures for MSSP clients are capped at 95 percent of the cost of nursing home care in the State. MSSP has had a Medicaid 2176 waiver since 1983. Federal funds provided under the waiver are channeled through the State Department of Health Services to the Department of Aging which administers the program at the State level. The Federal funds are matched with State funds. As of 1987, there were 22 MSSP programs in 19 of the 58 counties of California. The programs are run by county departments of health and social services, other county and city government agencies, AAAs, hospitals, and private, nonprofit agencies.

The California Department on Aging also administers the *Linkages program*, which provides information and referrals and case management for elderly and disabled people who are at risk of nursing home placement but not eligible for nursing home care funded by Medi-Cal (California's Medicaid program). In general, Linkages clients are less impaired than MSSP clients. Linkages is funded entirely with State money, and some funds are available to purchase in-home and other community services for Linkages clients (101,354).

As of 1987, there were 13 Linkages programs in California. At the local level, the 13 programs were administered by a variety of public and private agencies: the City of Oakland Social Services Department; Community Care Management Corp. in Ukiah; Humbolt Senior Citizens Council in Eureka; Senior Care Action Network in Long Beach; Huntington Memorial Hospital in Pasadena; Altamed Health Services Corp. in Los Angeles; Mt. Zion Hospital and Medical Center in San Francisco; San Mateo County Department of Health Services; the San Diego County AAA; San Joaquin Department of Aging, Children's, and Community Services; Jewish Family Services of Los Angeles; Monterey County Department of Social Services; and Westside Center for Independent Living in West

¹³For more information about Family Survival Project and California's regional resource centers, see the discussion of Family Survival Project in ch. 8.

Figure 7-4---A Brochure Publicizing California's 11 Regional Resource Centers for the Families and Caregivers of Brain-Impaired Adults

Wherever You Live, There's Help

Resources for the Families and Caregivers of Brain-Impaired Adults



Regional Resource Centers operating in California

- 1 The Family Survival Project**
 425 Bush Street Suite 500, San Francisco
 CA 94108. (415) 434-3388, (800) 445-8106
 (CA) Serving Alameda, Contra Costa, Marin, San Francisco, San Mateo and Santa Clara Counties (Also State wide Resources Consultant)
- 2 Brain-Impaired Adults Resource Center for the Redwood Empire**
 212 Tucker Street, Healdsburg, CA 95448.
 (707) 431-1123, (800) 352-1666 (regional)
 Serving Del Norte, Humboldt, Lake, Mendocino, Napa, Solano and Sonoma Counties
- 3 Los Angeles Regional Resource Center for Caregivers of Brain Impaired Adults**
 3715 McClintock, University Park, MC 0191
 Los Angeles, CA 90089 **0191 (213) 743-8-ii, (800) 540-4442** (LA County only) Serving Los Angeles County
- 4 Inland Counties Resource Center**
 155 West Hospitality Lane, Suite 123, San Bernardino, CA 92408, (714) 824-2461, (800) 423-6432 (CA). Serving Inyo, Mono, Riverside and San Bernardino Counties
- 5 Del Oro Regional Resource Center**
 3625 Mission Avenue, Suite 300, Carmichael, CA 95608, (916) 971-0893, (800) 635-0220 (regional). Serving Alpine, Amador, Calaveras, Colusa, El Dorado, Nevada, Placer, San Joaquin, Sacramento, Sierra, Sutter, Yolo and Yuba Counties.
- 6 Southern Regional Resource Center**
 3665 Ruffin Road, Suite 110, San Diego, CA 92123, (619) 541-4432. Serving Imperial and San Diego Counties.
- 7 Coast Regional Resource Center**
 829 De La Vina, Suite 120, Santa Barbara, CA 93101, (805) 965-4775, (800) 443-1236 (regional). Serving San Luis Obispo, Santa Barbara and Ventura Counties
- 8 Mountain Regional Resource Center**
 2nd and Normal Streets, Chico, CA 95929-0794, (916) 895-5925, (800) 822-0109 (regional). Serving Butte, Glenn, Lassen, Modoc, Plumas, Shasta, Siskiyou, Tehama and Trinity Counties
- 9 Valley Regional Resource Center**
 2491 West Shaw Avenue, Suite #102, Fresno, CA 93710, (209) 225-6748, (800) 541-8614 (regional). Serving Fresno, Kern, Kings, Madera, Mariposa, Merced, Stanislaus, Tulare, and Tuolumne Counties
- 10 Del Mar Regional Resource Center**
 11 Maple Street, Suite B, Salinas, CA 93901, (408) 424-4359, (800) 624-8304 (regional) Serving Monterey, San Benito and Santa Cruz Counties.
- 11 Orange Regional Resource Center**
 111 W. Bastanbury Road, Suite 1-J, Fullerton, CA 92635, (714) 680-0122, (800) 543-8312 (regional). Serving Orange County

continued



George Deukmejian, Governor
Clifford L. Allenby, Secretary
 California Health and Welfare Agency
D. Michael O'Connor, M.D., Director
 California Department of Mental Health

As approved by the Department of Mental Health and directed by The Family Survival Project.

SOURCE: Family Survival Project, "Wherever You Live, There's Help," California Department of Mental Health, Sacramento, CA.

Los Angeles. All but the last two agencies also run MSSP programs (101).¹⁴

Another program of California's Department on Aging, the *SEED Community Long-Term Care Project*¹⁵ does not directly link individuals to services; instead, the SEED program encourages coordination of long-term care services in local communities, primarily through the development of integrated screening and intake procedures and the use of a uniform assessment instrument by different agencies that provide services (101,354,714). In 1986, the State Department on Aging designated 11 SEED communities. The SEED lead agency in most of the 11 communities was the AAA, but in 2 communities, it was the county department of social services and in 1, the county department of health services. Of the 11 SEED communities, 9 have an MSSP program, and 7 have a Linkages program, but these MSSP and Linkages programs are not necessarily administered by the SEED lead agency. In some SEED communities, the program has served as a catalyst for the coordination of programs of the California Department on Aging (e.g., MSSP and Linkages) and the involvement of agencies that administer programs of the State Departments of Social Services and Mental Health, and other agencies.

The California Department on Aging also funds a program of *Community-based Respite Care Services* in eight areas of the State. The local agencies that administer this program recruit and train respite care workers and provide information about and referrals to respite care for adults with chronic physical or mental impairments. Although the program is not dementia-specific, people with dementia and their caregivers are among its primary clients (460). The local agencies that administer the program include two AAAs, a hospital, a community health center, two senior citizens agencies, and two agencies that serve disabled people.

Finally, the California Department of Social Services administers the *In-Home Supportive Services (IHSS)* program, which provides case management and in-home personal care and chore services for people of all ages with monthly income of \$726

to \$1,051 (depending on their degree of functional impairment). The program is funded with Federal Social Services Block Grant monies and other State funds. It is administered at the local level by county departments of social services (354).

In the early 1980s, an attempt was made to consolidate long-term care services for elderly and disabled people in California under a single State department. In 1982, the California Legislature passed a bill (AB 2860) to create a State Department of Aging and Long-Term Care and to authorize the new department to pool funds from various sources to provide services for elderly and disabled people. The 1982 bill created a task force to make recommendations to the governor and the legislature pertaining to the implementation of its provisions. In the following year, however, agreements and compromises that had been worked out previously among the interest groups that had supported the bill broke down. The greatest disagreement occurred between aging and disability interest groups, each of which feared that implementation of the bill might reduce overall funding for services for its constituents. Because of the disagreement, the California Legislature passed a substitute bill (AB 2226) in 1984. The new bill created a Division of Long-Term Care in California's Department on Aging and assigned that department primary responsibility for developing a long-term care system, but it abandoned—at least temporarily—the goal of consolidating all long-term care services into a single State department. Instead, the bill authorized several initiatives to coordinate services at the community level (362,746). The Linkages and SEED programs described earlier were two of those initiatives (101,714).

In addition to State-funded and/or State-administered linking programs, California has many public and private agencies that link people with dementia to services. They include Alzheimer's Association chapters and other voluntary organizations that represent people with dementia and their caregivers; community mental health centers; community health centers; local government agencies; hospitals; private social service, family service, and home

¹⁴Altamed Health Services, a community health center in Los Angeles that operates an MSSP program and a Linkages program, is described in box 8-E of ch. 8.

¹⁵When this program was first envisioned, SEED was selected as an acronym to describe the "service-enriched" areas that were to be the focus of the program. The Department continued to use the name SEED when the approach was broadened to include communities with only modest or moderate resource levels (714).

health agencies; and adult day centers. California also has 2 of the 15 Alzheimer's Disease Research Centers funded by the National Institute on Aging; they are located at the University of California in San Diego, and the University of Southern California in Los Angeles. As noted in the discussion of New York's linking programs, Alzheimer's Disease Research Centers are primarily biomedical research facilities, but they also provide educational programs about dementia for the public and information and referrals for people who are involved in their clinical research programs.

Summary and Implications for a National System to Link People With Dementia to Services

Many States have linking programs-i.e., public education, information and referral, outreach, and case management programs-that serve at least some people with dementia. The programs are diverse, but some generalizations can be made:

- Some States have dementia-specific information and referral programs (sometimes in addition to the State's information and referral programs for elderly people or people of all ages). State outreach and case management programs generally are not dementia-specific, however. (Public education about dementia and services for people with dementia is, by definition, dementia-specific.)
- Dementia-specific State programs tend to be new, whereas many of the programs intended to serve elderly and disabled people in general have been in existence longer.
- Many, although certainly not all, of the dementia-specific programs (primarily public education and information and referral programs) are programs of State departments, divisions, or commissions on aging. In contrast, case management programs, which generally are not dementia-specific, are administered and/or funded by a variety of State agencies.
- In many States, public education and information and referral are provided through the same program, but active outreach and case management are provided through other programs. Thus, the four functions identified by this OTA assessment as essential components of an effective linking system for people with dementia are not provided through the same program.

Despite these generalizations, the main conclusion to be drawn from the preceding section is the diversity of existing State linking programs. They vary in terms of the State agencies that administer and/or fund them, the local agencies that implement them, the linking functions and other services they provide, and the people they serve.

As noted at the beginning of this chapter, the diversity of existing State linking programs makes it difficult to design a national linking system that would build on rather than duplicate or disrupt the programs. Clearly, there is no single type of State agency that administers most of the existing programs and is therefore the obvious choice to administer a national linking system. State aging agencies (departments, divisions, commissions, etc.) probably administer more of the existing linking programs than any other type of State agency, but many other types of State agencies also administer these programs. Moreover, in many States, several State agencies administer linking programs. Each of the State agencies that administers a linking program has a constituency of clients that benefit from its program and of agencies and individuals that implement the program at the community level, all of whom have a stake in the continuation of the existing program. If Congress mandated a single category of agencies to constitute a national linking system, that decision would undoubtedly engender resistance from the State agencies that administer existing linking programs. Likewise, such a decision would engender resistance from the agencies and individuals that implement the existing State linking programs at the community level but were not chosen to implement the national system.

The preceding discussion of State programs that link people to services focused attention on the States that have such programs. The number of States that provide and/or fund public education, information and referral, outreach, and case management programs that serve at least some people with dementia is impressive and is growing. On the other hand, it is also true that some States do not have programs that link people with dementia to services or have programs that only serve a small percentage of all people with dementia and their caregivers. All States have case management programs, for example, but many of the programs serve only people with very low income and people who are so ill or functionally impaired that they are eligible for Medicaid-funded nursing home care. Therefore,

although many States have linking programs that serve at least some people with dementia, many people with dementia still are not served. In addition, since the four functions identified by this assessment as essential components of an effective linking system for people with dementia are not provided through the same program, some people with dementia and their caregivers “fall through the cracks” between programs.

STATE AND COMMUNITY SERVICE SYSTEMS

In addition to, or instead of, establishing public education, information and referral, outreach, and case management programs that are added to the existing service environment, some States and communities have made fundamental changes in the existing service environment by coordinating agencies’ functions and pooling funding sources to create a consolidated service system. These systems, through which people are connected to services, are often referred to as “long-term care systems.” They generally connect their clients to a range of services, including many of the health care, long-term care, social, and other services that may be needed for a person with dementia.

Several topics related to State and community consolidated service systems are addressed in the following sections. The first topic considered is why some States and communities have created consolidated service systems. The second is what types of changes are involved in developing such systems. Also discussed below are the consolidated long-term care service systems in three States (Oregon, Wisconsin, and Illinois) and four communities. The concluding section of the chapter discusses some findings of long-term care demonstration projects that have influenced the development of State and community service systems.

Each of these topics could be the subject of a full report. OTA’s objective here is only to provide a brief overview of State and community service systems in order to point out some of the ways in which such systems differ from the linking programs described in the previous section of this chapter and to consider the current and potential role of such systems in linking people with dementia to services. For more information on State long-term care service systems, the interested reader is referred to the following publications:

- *Building Affordable Long-Term Care Alternatives: Integrating State Policy*, published by the National Governors’ Association (586).
- *State Long-Term Care Reform: Development of Community Care Systems in Six States*, published by the National Governors’ Association (587).
- *State Financing of Long-Term Care Services for the Elderly*; published by the Intergovernmental Health Policy Project (353,354).

OTA’s analysis below draws heavily from these publications.

Why Some States and Communities Have Developed Consolidated Long-Term Care Service Systems

The States and communities that have developed consolidated long-term care service systems have done so for several interrelated reasons. One reason is to reduce the complexity and fragmentation of the service environment so that people can connect to the services they need (353,362,587). The extreme complexity of the service environment in many communities was discussed in chapters, 1 and 2. Health care, long-term care, social, and other services may be provided by many different agencies and individuals. Likewise, there are many potential sources of funding for services. Each service provider and funding source has complex rules that restrict what services are provided or paid for and who can receive them. Often, an individual’s service needs cannot be met by a single agency, so the person must either interact with several different agencies *or* forgo needed services. By coordinating agencies’ functions and pooling funding sources, some States and communities hope to make it easier for people to connect to appropriate services.

A second reason why some States and communities have developed consolidated long-term care service systems is to limit unnecessary use of nursing home care. In 1986, public spending for nursing home care amounted to \$18.1 billion—87 percent (\$15.8 billion) of which was from Medicaid (828). Because of the growth in the size of the elderly population—particularly growth in the age group over 85, which is most at risk of nursing home placement—there has been, and continues to be, concern that nursing home use will increase greatly and that Medicaid expenditures for nursing home care will rise accordingly (362,372). To address that

problem, States have instituted a variety of measures. Many States have certificate-of-need programs to limit the creation of new nursing home beds. Many States have also initiated nursing home preadmission screening programs to evaluate nursing home applicants and divert those who can be cared for at home (666). In addition, some States and communities have developed consolidated service systems to facilitate the targeting of services to people at risk of nursing home placement, thereby enabling them to remain in their homes (362,372).

A third reason why some States and communities have developed consolidated long-term care service systems is to create an organizational and administrative structure that allows for efficient and appropriate use of limited services and funds:

- by targeting available services to the people who need them most, especially those at risk of nursing home placement;
- by avoiding duplication of local agencies' efforts, particularly repeated assessments of the same person by each agency that provides services for the person; and
- by increasing administrative control and accountability for the use of public funds.

A major objective of the States that have developed consolidated long-term care service systems is to shift some of the public funds now spent on nursing home care to in-home and community services (353,362,374,587). (As of 1987, more than 80 percent of Federal and State spending for long-term care for elderly people went for nursing home care, leaving less than 20 percent for in-home and other community services (353).)

None of the reasons and objectives just cited are incompatible with the goal of linking at least some people with dementia to appropriate services. The fact that some State and community service systems focus on limiting the use of nursing home care and targeting services to people who are eligible for or at risk of nursing home placement means, however, that the linking functions performed by these systems often are not available to people who are not eligible for or at risk of institutionalization-including many people with dementia.

Changes Involved in Developing a Consolidated Service System

The development of a consolidated service system may involve several different kinds of changes in agencies and procedures at the State and community level, including:

- the designation of a single State agency to administer all the Federal and State programs that pay for services;
- the designation of a single agency at the community level to administer services paid for by all Federal, State, and local government programs;
- the pooling of funds from different programs to pay for services; and
- the establishment of a uniform client assessment procedure, including the use of a common assessment instrument, for services paid for by various programs.

Historically, each State has established agencies to administer health care, mental health, social service, public assistance, and other programs. Typically, the structure and functions of existing State agencies has been adjusted to incorporate new Federal and State programs enacted over the years. For each new Federal or State program that has been established, some States have created a new State agency; some have created a new division in an existing State agency; and some have expanded the functions of an existing State agency. The creation of new State agencies or divisions to administer new Federal programs has been fostered by the distinct and often inflexible rules and regulations that have accompanied each new Federal program (353).

In 1987, the Intergovernmental Health Policy Project surveyed the 50 States and the District of Columbia to determine how they were financing and administering services for elderly people (353). The survey gathered information about State agencies that administer Medicaid, Medicaid 2176 waiver programs, the Older Americans Act, the Social Services Block Grant, State supplemental payments to elderly people receiving Federal Supplemental Security Income payments, and State general funds that pay for services for elderly people. The 1987 survey found that:

- 1 State (Oregon) was using the same agency to administer all the Federal and State-funded programs and services that were studied,

- 19 States were using 2 State agencies or divisions to administer the programs and services,
- 24 States were using 3 agencies or divisions to administer the programs and services, and
- 7 States were using 4 agencies or divisions to administer the programs and services (354).

The 1986 survey did not ask about State agencies that administer mental health services or services for nonelderly disabled adults. In some States, those services, which may benefit people with dementia, are administered by still other State agencies.

The designation of a single State agency to administer all the Federal and State programs that pay for services for elderly and disabled people requires a State to overcome substantial barriers—barriers created by the inflexible rules and regulations of each Federal program, barriers created by organizational and turf issues that cause resistance to change in existing State agencies, and barriers created by concerns of various interest groups that the consolidation of programs and funding sources at the State level will reduce overall funding for the client population they represent. For these and other reasons, States that have developed consolidated service systems have moved slowly in merging administrative authority for different programs at the State level, and some of those States have instead created an umbrella State agency or an interagency coordinating group to oversee the different State agencies that administer the programs (587).

The other three kinds of changes that may be involved in creating a consolidated service system—the designation of a single agency at the community level to administer services funded by all Federal, State, and local programs, the pooling of funds from different programs to pay for services, and the establishment of a uniform client assessment procedure—also require overcoming barriers created by inflexible program rules and regulations, by organizational and turf issues that cause resistance to change, and by interest group concerns. States and communities that have developed consolidated service systems generally have moved slowly and incrementally in implementing these changes.

Three other mechanisms are frequently part of consolidated service systems, but, unlike the four kinds of changes already discussed, these three mechanisms can be implemented by a single agency in a State or community without changing the

structure or functions of other agencies. The three mechanisms are:

- case management,
- nursing home preadmission screening, and
- contracts with service providers.

All State and community consolidated service systems include case management as a major component. In fact, consolidated service systems are sometimes referred to as “case-managed systems.” The role of the case manager in such systems is often quite different from the traditional case management role in which the case manager coordinates or “brokers” services from various community agencies for an individual client; in a consolidated service system, a case manager more often administers and allocates services that are already coordinated by the structure and functions of the system. Many analysts have noted the distinction between the coordination or brokering of services for an individual client from various community agencies and coordination of services through a service system (see, e.g., Austin et al. (47), Kodner and Feldman (423), and Zawadski (939)). That distinction is not always recognized, however, and some people wrongly assume that case management by itself creates a consolidated service system.

State consolidated service systems generally include nursing home preadmission screening programs as a component. As of 1986, 29 States and the District of Columbia had nursing home preadmission screening programs; in addition, some States had programs to coordinate or fund in-home and community services for people whom the preadmission screening program found ineligible for nursing home care (356). In 1987, a Federal law was enacted that required States to establish a nursing home preadmission screening program to identify mentally ill and mentally retarded people for whom nursing home placement is inappropriate (Public Law 100-203). OTA does not know how the preadmission screening programs that are developed in response to the 1987 law will function with respect to preadmission screening programs that predated the law; nor does OTA know how many of the new programs coordinate, provide, or fund in-home and community services for people who are ineligible for nursing home care. Clearly, however, not all nursing home preadmission screening programs are part of a consolidated service system, and by themselves, nursing home preadmission screen-

ing programs do not create a consolidated service system.

Lastly, most State and community consolidated service systems contract with agencies and individuals to furnish services to their clients. Some agencies that are not part of a consolidated service system also contract with other agencies to provide services for their clients. Although an agency's contracts with other service providers undoubtedly facilitate access to care for the agency's clients, contracts for services do not by themselves create a consolidated service system.

Three States' Consolidated Service Systems

Oregon, Wisconsin, and Illinois are three States that have gone farther than most in creating consolidated service systems through which people are connected to services. Their service systems are described briefly below. The emphasis in the discussion is on the changes that were made to develop each system and the difficult organizational and turf issues that had to be addressed in the process.

Oregon's Consolidated Long-Term Care Service System

In Oregon, all publicly funded long-term care services for elderly and disabled people are administered by a single agency at the State level—the Division of Senior Services—and a single local agency in most communities (433). The Division of Senior Services and the local agencies administer Medicaid, a large Medicaid 2176 waiver program, Older Americans Act funds, Social Services Block Grant funds, and Oregon Project Independence, a State-funded program that provides in-home and community services for people over age 60.

The development of Oregon's consolidated service system began in the mid-1970s as a result of the State's concern about increasing nursing home costs (434). In 1975, Oregon Project Independence was established by the State with the objective of substituting in-home and community services for nursing home care. In 1980, Oregon initiated a nursing home preadmission screening program and a long-term care demonstration project that paid for expanded in-home and community services in four counties; the main focus of Oregon Project Independence was coordination of the various agencies that provided and paid for services—'getting every-

body to talk the same language and plan the same actions" (434).

Late in 1980, the Oregon Department of Human Resources developed a proposal to consolidate the administration of aging and long-term care services in a single State agency. The proposal was rejected by other State and local agencies and by advocates for the elderly because they had not been involved in the planning process. Following the proposal's rejection, the governor appointed a planning committee that met weekly for several months and involved more than 100 people in its planning process. The planning committee's work and deliberations by the Oregon Legislature resulted in a 1981 law that created Oregon's Division of Senior Services by merging the functions of the State aging agency and the long-term care division of the State Medicaid agency. Each AAA in Oregon that was part of local government (i.e., counties or councils of government) was given the option of becoming the single agency to administer all publicly funded services for elderly and disabled people at the local level. Under the 1981 law, AAAs that were private nonprofit organizations were allowed to administer Older Americans Act and Oregon Project Independence services, but a district office of the Senior Services Division still had to perform Medicaid-related functions, including nursing home preadmission screening. Most AAAs that were given the option of administering all the services chose to do so. As of 1987, 11 of the Oregon's 18 AAAs were administering all publicly funded services for elderly and disabled people (434,587).

When the State law creating the Division of Senior Services passed in 1981, Oregon applied for a Medicaid 2176 waiver to increase the availability of in-home and community services. Oregon's waiver proposal, which was based on the four-county demonstration project begun the previous year, was approved by the Federal Government in less than a month (434).

The implementation of all these changes led to significant tension and disagreements among the State agencies, AAAs, service providers, and aging and disability advocacy groups in Oregon. In 1984, the State took the unusual step of hiring a consultant to conduct a formal negotiating process. That process, in which representatives of each group met for 1 day every other week for over 6 months,

eventually resolved most of the major areas of disagreement (434,587).

By combining Federal and State funds from various programs, the State of Oregon can provide case management and in-home and community services to many elderly and disabled people. Still, Oregon's long-term care system does not serve every person who needs help. Services generally are targeted to people who are severely functionally impaired and people with low incomes, although some services are not means-tested or are provided on a sliding-fee-scale basis to people with higher incomes. Since 1983, the State of Oregon has provided case management for some elderly and disabled people who are not otherwise eligible for services due to their income or level of impairment (434,587). As of July 1989, Oregon had allocated funds for in-home and community services for some people with Alzheimer's and related dementias who are under age 60 and have not been eligible for services previously (436).

Wisconsin's Consolidated Long-Term Care Service System

In Wisconsin, publicly funded long-term care services are administered at the State level by three units of the Wisconsin Department of Health and Social Services: the Division of Health, which administers Medicaid, and two bureaus of the Division of Community Services, which administer all other programs that provide in-home and community services (354,587). The coordination of these services occurs primarily at the county level. County government agencies administer Medicaid, Social Services Block Grant funds, and several small Medicaid 2176 waiver programs, as well as the Community Options Program, a State-tided program described below. The State of Wisconsin has six AAAs that are administratively separate from county government but allocate Older Americans Act funds to county government aging units.

In 1976, the Wisconsin Lieutenant Governor's office initiated demonstration projects in four counties to substitute in-home care for nursing home care. Although the demonstration projects were considered unsuccessful by some people, in part because they were not administered by county government, they did create experience and knowledge about how to provide community care (587).

In the late 1970s, Wisconsin had a very high ratio of nursing home beds to elderly residents as compared to the ratio in other States, and Medicaid spending for nursing home care was increasing rapidly. To address that problem, the State convened people from State and local agencies, researchers, advocates, and nursing home administrators. According to one observer, the meetings resulted in "organizational fratricide and conceptual chaos:

Within minutes, these official planning sessions evolved into the great ritual debates of long-term care policy. Health care providers and social service agencies quickly were accusing each other of failing to integrate. The partisans of a particular functional assessment tool rushed to ridicule the conceptual flaws and inaccuracies of everybody else's preferred tool . . . The administrators of means-tested programs belittled the lack of targeting of non-means-tested programs. In one corner there was a centralization v. decentralization debate. And everybody who was not involved in the conceptual controversies was whispering to each other the real question, Who is going to get the contracts? (594).

Having failed with this approach, the State of Wisconsin tried instead asking consumers of long-term care services--elderly and physically disabled people and families of developmentally disabled people--what kinds of services and programs they needed (594). State officials believe the system finally put in place in Wisconsin reflects these consumers' preferences.

In 1981, the Wisconsin Legislature enacted a moratorium on nursing home bed expansion. At the same time, it established the Community Options Program. The Community Options Program is a State-funded program that provides case management and in-home and community services for elderly, physically disabled, developmentally disabled, chronically mentally ill, and chemically dependent people, including both children and adults. It began in eight counties in 1982 and was extended to the whole State by 1986. The Community Options Program makes State funds available to counties to provide case management and services for people who are assessed as requiring nursing home care. The State of Wisconsin does not specify what services shall be covered, encouraging complete flexibility in meeting individual needs, but per person expenditures averaged across a county's caseload cannot exceed the State's share of the cost of nursing home care for an individual (354,587).

Counties in Wisconsin can administer the Community Options Program through the county social services department (which administers other programs for elderly and physically disabled people) or through a "county 51 board" (which administers programs for mentally ill, developmentally disabled, and chemically dependent People).¹⁶ As of 1987, 80 percent of counties in the State were using a county social services department to administer the Community Options Program, and 20 percent were using a "county 51 board." The State of Wisconsin does not require that counties use a uniform client assessment procedure, but there is a recommended assessment instrument (587).

Like Oregon's system, Wisconsin's long-term care service system targets services to people who are severely functionally impaired and people with low income (354,587). Services are provided free to individuals with income below a given threshold and on a sliding-fee-scale basis to individuals with incomes above the threshold. Assessment and care planning are provided to anyone who may need long-term care, without regard for the person's income.

In 1986, the State of Wisconsin extended eligibility for case management and services through the Community Options Program to people in the early and middle stages of Alzheimer's disease who are not yet severely functionally impaired. In addition, the State provides grants of up to \$4,000 a year for families who are caring for a person with dementia, as long as the income of the individual and his or her spouse is \$40,000 or less. In some cases, the grant funds are given directly to the families, but more often they are used to purchase services for them. Overall funding for the grant program is capped, however, so not all families who are eligible actually receive grants (587,918). As noted earlier in this chapter, Wisconsin also funds the Alzheimer's Information and Training Center, which is operated by the Southeastern Wisconsin Alzheimer's Association Chapter.

Illinois' Consolidated Long-Term Care Service System

In Illinois, publicly funded long-term care services are administered at the State level by three State agencies. Long-term care services for elderly people

are administered by the Illinois Department of Public Aid (which administers Medicaid) and the Illinois Department of Aging (which administers Older Americans Act funds and Illinois' Community Care Program, which provides case management and three services-homemaker, adult day, and chore services-for people over age 60 who are eligible for nursing home care). Services for disabled people under age 60 are administered by the Illinois Department of Rehabilitation. At the State level, the coordination of services administered by these three agencies occurs through an interagency coordinating group. At the local level, coordination occurs through "case coordination units" -public and private agencies designated by the State to implement the State's Community Care Program (587).

The development of Illinois' long-term care service system began in 1977 with the initiation of pilot programs that provided in-home services in three areas of the State and the passage of a bill to provide certain in-home and adult day services on a statewide basis. At first, the services were administered by the Illinois Department of Public Aid. Because aging advocacy groups objected to the "welfare stigma" associated with that department, however, administrative responsibility for the services was shifted in 1979 to the Illinois Department on Aging. This department allocated funds for services to the State's 13 AAAs; and the AAAs, in turn, provided case management and purchased services for eligible clients. That arrangement lasted 1 year and was then replaced by a system in which the State of Illinois contracted directly with community agencies to provide both case management and services for eligible people (587).

Over time, waiting lists developed for services provided by Illinois' Community Care Program (587). In 1982, a class action suit filed on behalf of people on the waiting lists resulted in a court decision that prohibited waiting lists for the program, in effect making it an entitlement program. To control the overall cost of the Community Care Program, the State of Illinois instituted sliding-scale fees for services. The State also obtained more funds for the program through a Medicaid 2176 waiver. Lastly, the functions of case management and service provision were separated to avoid the

¹⁶ "County 51 boards" are local boards designated under Chapter 51 of Wisconsin's statutes to administer community mental health, developmental disabilities, alcoholism, and drug abuse programs.

possibility that case managers who worked for agencies that provided services would authorize more of their agencies' services than clients needed. The State of Illinois contracted directly with some community agencies to be 'case coordination units' to provide client assessments, care planning, and ongoing case management, and the State contracted with other agencies to provide services. Case coordination units are not allowed to provide services for Illinois' Community Care Program.

As of 1987, one-third of Illinois' 63 case coordination units were home health agencies; another one-third were senior service agencies; and the remainder were health care, mental health, family service, and social service agencies. All the case coordination units use a common client assessment instrument. They do preadmission screening, but they do not determine financial eligibility for Medicaid, a function performed by local offices of the Illinois Department of Public Aid (587).

Like Oregon's and Wisconsin's systems, Illinois' consolidated service system targets long-term care services to people who are severely functionally impaired and to people with low incomes. To be eligible for services through Illinois' Community Care Program, individuals must have less than \$10,000 in liquid assets. Individuals whose monthly income is below the Medicaid eligibility level receive services without any charge. Those whose monthly incomes exceed that level must pay a fee based on a sliding scale. The case coordination units receive Older Americans Act funds to provide assessments and care planning for people who are not eligible for the Community Care program (587). Case managers who work for the case coordination units receive special training about Alzheimer's and other dementias (345).

Four Communities' Service Systems

Some communities have developed or are developing service systems to rationalize the local service environment, reduce duplication of efforts by agencies that deal with the same client, and help people connect to appropriate services. The following sections describe four such systems:

- in Tulsa, Oklahoma;
- in Linn County, Iowa

- in three counties in northern New Hampshire; and
- in four counties in northwestern Ohio.

The systems described differ in ways that reflect the characteristics and needs of the communities they serve and the types of agencies already in place in those communities. Two of the systems (the ones in Tulsa, Oklahoma, and Linn County, Iowa) serve elderly people in general, and two (those in northern New Hampshire and northwestern Ohio) are dementia-specific. Each of the four systems was developed and is operated by a consortium of public and private agencies.

Tulsa's Long-Term Care Management Authority (Oklahoma)

In 1987, Tulsa, Oklahoma, established the Nation's first public long-term care management authority (557). Six agencies participated in its establishment:

1. the local AAA,
2. the State Medicaid agency,
3. the Veterans Administration (VA),
4. the city of Tulsa,
5. the county of Tulsa, and
6. the United Way.

Tulsa's Long-Term Care Management Authority was built on the success of an earlier effort to coordinate home care services by a consortium of local agencies (557). In 1983, five public and private agencies that were funding home health aide, homemaker, companion, and chore services in Tulsa agreed to establish a joint process to contract for the home care services they funded. The five agencies agreed on a uniform definition of each service, units of service, reporting requirements, and standards of care for the services, and in 1984, they issued a joint request for proposals to identify qualified home care providers. A committee with representatives from each agency and various citizen advisory groups reviewed the proposals from home care agencies and selected one agency to provide services that would be paid for by the five funding agencies. Subsequently, a home care assessment team was setup to monitor the quality of the services, and procedures were developed to ascertain clients' satisfaction with services and the satisfaction of referral sources

¹⁷The client satisfaction questionnaire developed for this purpose is shown in figure 5-4 in ch. 5.

such as physicians and hospital discharge planners.¹⁷

Based on the success of the previous effort, Tulsa's Long-Term Care Management Authority was established in 1987 to create a single administrative structure that would pool funds and coordinate the delivery of services (557). The organizers of the authority hope that it eventually will coordinate the delivery of all services—acute and long-term care services; in-home, institutional, and community-based services; and publicly and privately funded services. The Long-Term Care Management Authority's first project is a pilot case management program. The pilot program is funded by the Federal Administration on Aging and is intended to provide extended case management for elderly Medicaid and VA clients and to coordinate services provided by various agencies for the same client. A computerized information management system has been developed for the pilot program.

Linn County's Case Management Demonstration Project (Iowa)

The Linn County Case Management Demonstration Project was established in 1981 by a consortium of public and private agencies that provide services for elderly people in Linn county, a rural county in Iowa (80). The agencies in the consortium include the local AAA, which initiated the project; plus the local mental health, family service, United Way, substance abuse, and community action agencies; two hospitals; three home health agencies; an adult day center; a senior center; and two county government agencies. These agencies use a uniform assessment instrument to evaluate elderly people who come to them for services. A case management team composed of representatives of the agencies meets regularly to review new cases, develop care plans, and assign responsibility for managing each new client care to one of the agencies in the consortium.

In the first years of the Linn County Case Management Demonstration Project, the participating agencies took turns arranging and conducting meetings of the case management team (80,463). In 1986, a coordinator was hired for the project by the Linn County Department of Human Resource Development. Now the member agencies send completed assessment forms to the coordinator who arranges the team's bimonthly meetings. Having a

project coordinator has increased the number of cases that can be reviewed and allows for more efficient client tracking. The project has developed a client appeal process and standards for case management, confidentiality, and quality assurance. In the view of its member agencies, the project has reduced fragmentation and duplication of services and minimized turf issues among the agencies.

The North Country Alzheimer's Partnership Project (New Hampshire)

The North Country Alzheimer's Partnership Project, which links people with dementia and their families to services in three rural counties in northern New Hampshire, was created in 1987 by a consortium of public and private agencies (551,614). The project is funded by a 3-year grant from the National Institute of Mental Health. The New Hampshire Divisions of Mental Health and Developmental Services and Elderly and Adult Services coordinate the administration and evaluation of the project.

Individualized care plans are developed for clients of the project on the basis of a comprehensive in-home assessment conducted by nurses from local home health agencies and a social worker from the local Tri-County Community Action Agency. Ongoing case management is provided by Crotched Mountain Community Care, Inc., a private, non-profit case management agency. Information and referral, public education, family support groups, counseling, and support services are provided by staff of the Tri-County Community Action Agency. The project contracts with six home health agencies to provide in-home services (551,614).

The ACCESS Project in Northwestern Ohio

The ACCESS Project in northwestern Ohio is a project operated by a consortium of 10 public and private agencies that have been receiving funds from the State of Ohio since 1987 to provide people with dementia and their caregivers in a four-county area case management, caregiver education, and in-home and adult day services (156,196). Family Service of Northwest Ohio, a private, nonprofit agency, is the lead agency for the project. State funding for the project was \$55,000 for 7 months in fiscal year 1987, \$110,000 for fiscal year 1988, and \$88,000 a year for fiscal years 1989 and 1990. For in-home and adult

¹⁷The client satisfaction questionnaire developed for this purpose is shown in figure 5-4 in ch. 5.

day services, the ACCESS Project charges fees to patients and caregivers based on a sliding scale.

Everyone who receives services through the ACCESS project receives case management (196). The ACCESS Project initially charged patients and their caregivers fees based on a sliding scale for the initial patient assessment and ongoing case management, but eventually it stopped charging for these functions. The project summary gave the following rationale:

Due to the fact that the concept of assessment and case management is ill-defined among the general public, we had a great deal of difficulty explaining to people why they had to pay for that service. As a result . . . we consolidated assessment and the first several hours of case management time and packaged it into what we called a “personal consultant” model. We believed that the use of the “personal consultant” model would be more appealing to the types of caregivers we were getting. We also decided that the ACCESS Project would assume the cost of the service up to the first 6 hours of direct service provided to each client. Through trying this, we discovered that it was a bookkeeping headache to try to keep track of when the first 6 hours of direct service had run out, and once the first 6 hours had expired, we faced the same reluctance among the clients to pay for a service they still did not understand. At this time, we have totally stopped charging for that type of service and have assumed its cost in the project (196).

Despite caregivers’ reluctance to pay for case management, a 1989 survey of 69 caregivers who had received ACCESS services found that the great majority of them valued the information and emotional support provided by the project’s case managers (619).

ACCESS has a strong caregiver education program. One component of the program is educational workshops conducted in various locations by the East Center for Community Health. The other component is in-home caregiver education, conducted primarily by a nurse from the Medical College of Ohio who uses a video cassette recorder and tapes about Alzheimer’s disease to provide individualized caregiver education about dementia and services for people with dementia (156).

Summary and Implications for a National System To Link People With Dementia to Services

The most important observation to be made about the State and community consolidated service systems just described is that such systems are extremely diverse. The systems do have common elements—including, in the State systems, a method of coordinating the administration of various programs at the State level and, in all the systems, methods for coordinating local agencies’ functions—but there is great diversity even in these common elements. Oregon coordinates the administration of programs at the State level through a single State agency; Wisconsin uses a human service umbrella agency; and Illinois uses an interagency coordinating committee. Likewise, in each State, different types of agencies have been designated to administer services at the local level—AAAs in Oregon, county social service departments and ‘county 51 boards’ in Wisconsin, and many different kinds of public and private agencies in Illinois. In each of the community service systems, the consortium of public and private agencies that created the system has devised different methods for assigning responsibility for an individual’s care to a certain agency or assigning particular functions (e.g., client assessment, ongoing case management, provision of services) to specific agencies.

The second most important observation to be made about the State and community consolidated service systems is that considerable time and effort were required to develop the systems, and difficult organizational and turf issues had to be resolved in the process. Most of the systems were developed incrementally. Among the obstacles they faced were: 1) inflexible requirements and regulations of the Federal programs that pay for services, and 2) administrative and organizational characteristics of State agencies that were established in the past to implement Federal program requirements and, once established, are hard to change (436).

The State consolidated service systems described in the preceding sections differ from the community systems in several ways, although some of the differences are more in degree than in kind. First, the State systems coordinate services for elderly and disabled people in general, or, in the case of Wisconsin, all people who need long-term care; in contrast, some of the community service systems are

dementia-specific. Second, the State systems generally coordinate only the functions of public agencies or private agencies under contract to public agencies; in contrast, the community systems coordinate the functions of both public and private agencies. Lastly, the State systems rely more on formal organizational structures and mandated procedures for coordination; in contrast, the community systems seem to rely more on the development of informal working relationships among individual service providers and agencies.

In some ways, it may be easier to create a consolidated service system in a community than in a State because of the smaller number of agencies and individuals that must be involved in a community service system and because of the greater potential for dealing with organizational and turf issues through informal working relationships among individuals. On the other hand, communities lack the authority to allocate and target State funds for services and to designate a single agency at the local level to administer all Federal and State programs that pay for services. These functions require the involvement of the State.

If Congress designated a single category of agencies to constitute a national linking system, States and communities that have developed consolidated service systems which are administered by agencies other than the designated agencies would have to change their systems or, alternatively, accept the existence of several systems—an outcome they have already spent considerable time and effort to avoid. Conversely, if Congress allowed each State to select the agencies that would constitute the linking system in that State, States that have developed consolidated service systems could incorporate the components of the linking system into their existing service systems. Presumably, some States would designate consortiums of agencies to constitute the linking system in some communities, particularly communities where a consortium of agencies has already established a service system that links people to services.

Consolidated service systems reduce the complexity and fragmentation of the service environment for the people they serve and generally make it easier for those people to connect to appropriate services, but many of the existing systems do not serve all types of people with dementia. Some systems do not serve people under age 60 or 65, and

many State systems focus primarily or exclusively on low-income people and/or people who are severely functionally impaired. Targeting public funds for services to low-income people and people who are severely functionally impaired seems entirely appropriate, but such targeting is not necessarily appropriate for linking functions. People with dementia and their families need help in linking to services at all stages of the patient's illness, including the early stages when the patient is not severely impaired. Likewise, patients and families with all levels of income and assets and patients under age 60 or 65 need help in linking to appropriate services.

Another reason why some consolidated service systems may not be completely effective in linking people with dementia to services is because they emphasize case management more than the three other components that OTA has concluded are essential for an effective linking system (i.e., public education, information and referral, and outreach). Although the local agencies that administer long-term care services in Oregon, Wisconsin, and Illinois also provide or contract for information and referrals (436,587), the primary emphasis in some systems that administer long-term care services is on providing case management for people who are eligible for the services.

Service systems that emphasize case management more than other linking functions and provide case management primarily for low-income and severely impaired people do so partly because of resource limitations and partly because of the systems' objectives and mission (i.e., they are responsible for allocating publicly funded services to people who are eligible for the services). Any of the systems could be modified to provide all four linking functions, thus expanding their mission and objectives to include linking all kinds of people to services. To do so would require more resources.

Lessons From Long-Term Demonstration Projects for the Development and Operation of Long-Term Care Service Systems

Beginning in the 1970s, Federal, State, and local governments and private foundations sponsored many long-term care demonstration projects. The primary purpose of the projects was to demonstrate that making available expanded in-home and community services could reduce the use of nursing home care and ultimately reduce total expenditures

for long-term care. Case management was a central component of virtually all the demonstration projects.

Recently, Kemper and colleagues analyzed the findings of 16 long-term care demonstration projects (406,407).¹⁸ They found that the use of nursing homes was slightly lower among demonstration participants (i.e., the people who received case management and had access to expanded in-home and community services) than for members of control groups. On the other hand, the cost of case management and expanded in-home and community services for demonstration participants generally exceeded any savings realized because of participants lower use of nursing homes.

Other commentators who have analyzed long-term care demonstration projects, including the projects analyzed by Kemper and colleagues, have reached essentially the same conclusions (see, e.g., Capitman (112), Hedrick and Inui (312), Piktialis and MacAdam (662); and Weissert (896)). These commentators have pointed out that in order to produce cost savings, case management and expanded in-home and community services would have to be targeted more precisely to people who without the services would be very likely to be admitted to a nursing home and that such precise targeting is probably not possible at present.

In summarizing their findings and pointing toward future directions for research and policy debate, Kemper and colleagues said:

Based on a review of community care demonstrations, we conclude that expanding public financing of community services beyond what already exists is likely to increase costs. Small nursing home cost reductions are more than offset by increased costs of providing services to those who would remain at home even without the expanded services. However, expanded community services appear to make people better off and not to cause substantial reductions in family caregiving. *Policymakers should move beyond asking whether expanded community care*

will reduce costs to addressing how much community care society is willing to pay for, who should receive it, and how it can be delivered efficiently [emphasis added] (406).

Even though the long-term care demonstration projects generally did not show that the government could save money by substituting in-home and other community services for nursing home care, many of the demonstration projects evolved into ongoing programs.¹⁹ Furthermore, the long-term care demonstration projects produced valuable knowledge and experience in implementing long-term care service systems. That knowledge and experience, coupled with knowledge and experience derived from ongoing State and community service systems, can be helpful to other States and communities that are developing long-term care service systems.

A particularly valuable source of information about long-term care service systems is the National Long-Term Care Channeling Demonstration (502). The Channeling demonstration, which was funded by the U.S. Department of Health and Human Services from 1980 to 1985, tested two case management models:

- . a “basic” model, in which case managers helped clients locate and arrange services but had very limited funds to purchase services for them; and
- . a “financial control” model, in which case managers not only helped clients locate and arrange services but had substantial funds to purchase services for them.

Case managers in the financial control model were much more involved than case managers in the basic model in allocating services and funding for services. Therefore, some findings of the demonstration about differences between the two models are relevant to one of the major policy questions raised in chapter 1—whether the agencies that are selected to constitute a national linking system should also allocate services and funding for services. Case managers in the basic model, who were less involved

¹⁸The 16 projects Kemper and colleagues reviewed were: 1) the Worcester Home Care Project; 2) National Center for Health Services Research Day Care/Homemaker Experiment; 3) Triage; 4) Washington Community-Based Care; 5) the ACCESS Project; 6) Georgia Alternative Health Services; 7) Wisconsin Community Care Organization; 8) On Lok Community Care Organization for Dependent Adults; 9) Organizations Providing for Elderly Needs; 10) the Multipurpose Senior Services Project (MSSP); 11) South Carolina Community Long-Term Care; 12) the Nursing Home Without Walls Program; 13) New York City Home Care; 14) Florida Pentastar; 15) San Diego Long-Term Care; and 16) the Channeling Project (406,407).

¹⁹Triage, for example, evolved into Connecticut Community Care, Inc., a private nonprofit case management agency discussed in ch. 1. On Lok Senior Health Services, as discussed in ch. 8, continues as a consolidated service delivery system in San Francisco and is currently being replicated in several locations nationwide. The Multipurpose Senior Services Project (MSSP) in California and the Nursing Home Without Walls in New York are ongoing programs that were discussed earlier in this chapter.

in allocating services and funding for services, were able to spend comparatively more time on directly helping clients, whereas case managers in the financial control model spent more time on administrative tasks and paperwork associated with ordering services (502). Ongoing case management cost more in the basic model (\$51 per client per month) than in the financial control model (\$35 per client per month). Obviously, however, the average cost to the demonstration of services arranged for clients was much lower in the basic model (\$38 per client per month) than in the financial control model (\$471 per client per month) (501). Both models reduced unmet service needs and increased informal caregivers' confidence that they would receive needed services and their satisfaction with service arrangements, but these outcomes were greater in the financial control model than in the basic model (502).

The Channeling demonstration project also had findings that bear on another policy question raised in chapter 1—whether the agencies that are selected to constitute a national linking system should or should not be service-providing agencies (i.e., agencies that provide services that go beyond linking functions). The Channeling demonstration project was implemented in 10 sites across the country. Six of the host agencies were AAAs (503). The other four host agencies were service-providing agencies. According to Channeling staff, case managers in the four service-providing agencies were generally able to maintain their independence and not did overuse their own agencies' services in preference to other agencies' services (30). This finding counters one of the primary arguments against designating service-providing agencies to constitute a national linking system.

The Channeling demonstration project also generated information that pertains to the implementation of case management in a service system, including the impact of differences in the size of case managers' caseloads and the relative strengths and weaknesses of nurses and social workers as case managers in such systems (34,503). Other useful findings of the demonstration pertain to procedures for selecting and contracting with community service providers and monitoring the costs and quality of

services (503).²⁰ All of these findings are relevant to the design of a system to link people with dementia to services.

CONCLUSION

As described in this chapter, many States have programs that link at least some people with dementia to services, and some States and communities have service systems that link some people with dementia to services. The chapter has pointed out both the existence and the diversity of those programs and systems—factors that have sometimes been given insufficient consideration in the development of Federal programs and policies for health care, long-term care, social, and other services for elderly and disabled people.

As noted throughout the chapter, the diversity of State linking programs and State and community services systems makes it difficult to design a national linking system that will fit with the existing programs and systems. The next chapter describes 11 categories of agencies Congress might designate to constitute the linking system nationwide and discusses several reasons for designating a single category of agencies to constitute such a system. On the other hand, by designating a single category of agencies to constitute the system, Congress would risk duplicating or disrupting existing State linking programs and State and community service systems. For this reason, Congress might choose instead to allow each State to designate the agencies that will constitute the linking system in that State.

There are important differences between linking programs and consolidated service systems. Linking programs are easier to establish than consolidated service systems because the programs can be established at the State or community level without substantially changing the structure, functions, or relationships among existing agencies and without engendering the intense organizational and turf issues that must be overcome in the process of creating a consolidated service system. On the other hand, linking programs do nothing to reduce the fundamental complexity and fragmentation of the service environment, so the problems that patients and families encounter in connecting to appropriate

²⁰For more information about Channeling, the interested reader is referred to a publication of the U.S. Department of Health and Human Services, *The Evaluation of the National Long-Term Care Demonstration: Final Report: Executive Summary* (502). That publication summarizes the project results and lists 25 additional evaluation reports on specific aspects of the project and 12 training guides and technical assistance documents developed for it.

services because of the complexity and fragmentation of the service environment remain.

A few States and communities have gone a considerable way in creating consolidated service systems. Their purposes in developing these systems have been to reduce the complexity and fragmentation of services at the community level; to connect people to services they need; to gain control over public, and especially State, expenditures for health care and long-term care services; and ultimately to shift some of the public funds now spent on nursing home care to in-home and community services. These systems would be particularly likely to be

disrupted if Congress mandated a single category of agencies to constitute the national linking system.

Finally, the chapter has described linking programs and service systems that are intended to serve elderly people or people of all ages and linking programs and systems that are intended to serve only people with dementia. These programs provide alternate models for a national linking system. The pros and cons of mandating a linking system that is dementia-specific v. a system that is dementia-capable and dementia-friendly but not dementia-specific are discussed in chapter 1.